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# THE ROLE OF FAMILY RITUAL: THE ENHANCEMENT OF COPING AND MEANING IN GRIEVING THE LOSS OF A CHILD

by

CAROLYN CHARNLEIGH POUNDER ©

A thesis

submitted to the Faculty of Graduate Studies and Research

in partial fulfillment of the requirements for the degree of

**MASTER OF SCIENCE**

**I N**

**FAMILY ECOLOGY AND PRACTICE**

**DEPARTMENT OF HUMAN ECOLOGY**
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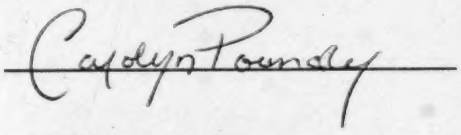

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Dianne K Kieren

**Dr. Dianne Kieren**

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**Dr. Norah Keating**

Marion Allen

**Dr. Marion Allen**

## Dedication

This thesis is in memory of
Adrien Gerald Michaud and
Lindsay Erin Roach
and is dedicated to all families
who have lost a child to
terminal illness.

*Outside our private envelopes of grief, life lights torches, sings songs, beckons with all its senses to draw us out. We must eventually open: take part. - Esteban Alviso*

ADRIEN GERALD MICHAUD
"CRITTER"
FEB. 02, 1986
MARCH 25, 1995

*Thought with his heart and loved unconditionally*

A Poem for My Friends

I ask you not to grieve with me;
For my loss you cannot know.
And please don't tell me how you understand,
But that is just how some things go.

I ask you not to know my pain,
Or to tell me it was God's will.
And please don't tell me how another child,
Will my ache and my need fulfill.

There are times when words are void of meaning.
There is nothing that anyone can say.
Just hold my hand and sit with me
'Til I can cope in a better way.

And when I mention Lindsay's name,
Please try not to look ashamed;
For I loved her more than life itself,
And I will always speak her name!

Do not tell me it should be over now,
And we cannot change the past;
You cannot understand, my friend,
This grief does not leave when asked!

Just bear with me in my grief,
And the turmoils of my mind.
And pray that on some future day
I'll not comfort you in kind.

## Abstract

In this rich case study, symbolic, sacred, creative, and healing elements of ritual were emphasized for their contribution to families coping with what is considered to be one of the most devastating losses a family can suffer, the death of a terminally ill child. Ritual's myriad forms, structures, and roles make it an ideal resource families can adapt according to their changing needs. Meaning, understanding, and acceptance are enhanced through ritual, helping family members to become closer and more resilient.

This research produced significant findings. While certain rituals were found valuable throughout the grieving process, structured, shared rituals were associated with coping in the last stages of life and early stages of loss, and unstructured, private rituals became more important as meaning developed. Families' initial efforts to cope with crisis gradually evolved into their ability to find and create meaning from their shared experience of lost dreams, hopes and expectations.

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I am indebted to the families who shared their stories of love and loss with me. The courage and wisdom they have gained from their experience is truly humbling.

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# CHAPTER I

## Introduction to the Problem

What is a child?

Parents may offer a variety of answers to this question. For many of us, a child may be someone to love, to be responsible for, to nurture, to guide and take care of; a person to bring us closer together, to strengthen our identity, to make the connection between our past and future more secure. A family.

Watch the facial expression of someone observing a young child at play. This simple scenario often inspires the mouth and eyes to crinkle into a smile. What might this little one represent? Continuity? New beginnings? The chance of something better? A future? Life itself?

For many of us a child signifies hope.

From the time a couple become aware they are going to have a baby, expectations of a promising future for the child and the family begin to take form. New parents may "plan" everything from "Whose smile will he have?" to, "What might her occupation be?", and "Won't we be proud at his wedding?" However, if that child becomes sick and dies, the thrilling anticipation of what might be is dramatically transformed into regret for what might have been. The end of a child's life not only represents the loss of dreams and expectations, but also a distortion of what we have come to understand as the natural order of being.

Until the twentieth century, deaths of children under the age of fifteen accounted for over fifty percent of the overall mortality rate

(DeSpelder & Strickland, 1994). Infant and child death would have, in earlier times, been a loss sustained by many, if not most, families with growing children. However, within the past hundred years vast improvements in water and sanitation, medical technology, health care, and nutrition have together contributed to an increased life expectancy. The same cohort now represents less than three percent of the mortality rate (DeSpelder & Strickland, 1994). With this dramatic shift in the social demographics of developed nations, the death of a child, once perceived as commonplace, is now viewed as an off-time event. Accordingly, the death of a child in today's society not only shocks a family's moral sense of right and wrong, it also shatters their logical and linear interpretation of how life ought to unfold.

Coping with the death of a son or daughter, or a brother or sister, involves a soulful and solitary search for meaning. While the entire family feels the weight of the loss, and may attempt to support each other through critical periods of emotional trauma, in many ways the struggle with grief is uniquely experienced by each member.

When a child has died, an exploration of story allows families the opportunity to give voice to their struggles and successes, their weaknesses and strengths, their hopelessness and hope (Jevne, 1994). The traveller embarks upon a lifelong journey, which offers the chance to rebuild and embrace life anew.

The first steps toward healing may be faltering and forced, but in time may fall into a more natural rhythm. And as the darkness of grief is lifted, different paths appear. It may be discovered along the

way that the relationship with the child is not lost, but is instead transformed, taking on new meaning and purpose (Clark, 1993).

Families engage in many activities in coping with their tragic loss. One such activity is the use of ritual. When family ritual is made part of a family's coping repertoire, avenues of caring, communicating, creativity, and celebrating emerge, revealing greater depths than could otherwise be known (Jevne, 1994).

***

## Research Purpose

This study has been conducted to further the understanding of how families cope and find meaning when faced with the loss of a child to terminal illness. Emphasis has been placed on the role of family ritual. In particular, this research seeks to decipher and understand how ritual facilitates coping and enhances meaning within this context. The ways in which coping progresses, meaning evolves, and ritual transforms over time also merit consideration.

Two families' experiences and insights collected through story will be described and contrasted to enhance the knowledge gathered in related research and practice, and thereby offer a valuable resource to be added to the coping repertoires of families facing a similar loss.

## Research Question

What role does family ritual play in the enhancement of meaning and coping in families who have experienced the terminal illness and the death of a child?

## Definitions

### Family rituals

Family rituals are culturally or personally meaningful acts which can be distinguished from custom and habit by their use of symbol (Imber-Black, 1988; Scheff, 1979). Their symbolic meaning gives them deeper significance than the acts themselves (Imber-Black, 1988). Through repetition, familiarity, and transformation of established knowledge, new behaviours, actions, and meanings can develop (Scheff, 1979). Tradition may yield to change, and relationships - both past and present - are redefined. The less structured parts of ritual give family members the freedom to attach subjective meaning to their experiences, while the more structured parts of ritual offer the family a sense of security for the expression of strong emotion, and direction to guide their actions. The way a family spends a religious or secular holiday, celebrates birthdays or other important milestones, communicates at a family meeting, mealtime, or bedtime, shares some quiet moments...all of these are rituals - provided that the family finds them somehow meaningful (Fulghum, 1995; Imber-Black, 1988; Scheff, 1979).

### Coping

Coping involves adaptation to change, stress, and crisis through the use of resources (McCubbin, Thompson, Allgood, Pirner, & McCubbin, 1988). This process may or may not involve conscious awareness and identification of the stress, crisis or resource (Hill, 1949; Koop, 1994; Koop & Keating, 1990). Certain responses to what is happening in one's life may be deliberate while others may be unintentional, innate, or unconscious. Understanding the problem,

and being able to identify accessible choices, alternatives, resources, and goals helps people feel that they have at least some control over their lives and the situations they face (McCubbin, et al., 1988). How a family copes is subject to general complexities related to group dynamics, and more specifically, to personal coping skills and family cohesiveness during times of trouble (McCubbin, et al., 1988). While crisis management and problem solving are to some degree addressed individually, adopting a unified approach can benefit family members and bring them closer together. Yet within the context of this study, it is recognized that a practice which has served a family at one time may not always do so, and what is functional for certain family members may not be so for others (Fulghum, 1995). Coping must, therefore, be assessed with these considerations.

The sacred element of ritual

A distinctive part of what compels us to discover and experience the meaning of ritual is the very sacredness of its nature, yet identifying what makes something sacred is often an elusive task. A unique moment that comes but once, a repeated event, a special place, an emotion deeply felt, a profound or personally meaningful thought, something treasured for its symbolic value or simply itself alone - these could all be examples of what denotes the term sacred (Fulghum, 1995). There is a spiritual, but not necessarily religious, connotation related to that which is defined as sacred; something that intimately connects a person or a group of people and what has become sacrosanct to them. The essential point is that it is the individual, or collective, that imbues the quality of

sacredness upon something, not that something is necessarily or inherently sacred within itself. It is largely the symbolic and sacred elements of family ritual that lay the foundation for meaning, thereby enabling families to cope with their loss. Progress with coping allows meaning and significance to further evolve.

The importance of ritual

While research in the area of coping with the terminal illness and death of a child exists, much of the current literature adopts a decidedly negative stance (Blotcky, 1985). Indeed, this experience often serves as the ultimate test of a family's strengths and can have far-reaching and devastating effects (Benstein, 1997; Clark, 1995; Walsh & McGoldrick, 1991). Yet with other potentially positive outcomes left virtually unrecognized, families who face this situation are left without tangible examples whereby they may be empowered to find a source of strength, unity, and closeness in the face of their undelineated loss. The empowerment process is critical to family members as it allows them to attach meaning to their experience (Imber-Black, 1988; Walsh & McGoldrick, 1991). The use of ritual by families coping with the terminal illness and death of an adult family member has been offered as an example of an empowering coping device (Fulghum, 1995; Imber-Black, 1988; McCubbin, et al., 1986). Yet again, in the case of children under the age of eighteen, this concept has remained essentially unexplored. Clearly, a thorough consideration of the potential benefits of adopting family ritual, when families are forced to cope with the crisis of losing a young family member, is required. It should be recognized that research

does not have to nullify or negate the painful aspects of this sorrowful situation in an examination of those that are hopeful.

Coping, family ritual, and meaning

It is thought that age, life experience, internal and external resources, knowledge and belief systems are some factors that have an impact on how individuals and families are able to cope (Cousins, 1989; Korner, 1970; Schneider, 1980; Siegal, 1986). There are circumstances under which familiar coping skills can be used favourably in the management of crises and problems. At other times, what has worked before does not continue to do so, and a new approach must be found (McCubbin, 1993). Resources of many kinds may prove suitable to the specific context involved. Ritual is a resource that can be easily adapted to suit a family's character, structure, needs and abilities in such a way as to assist in the coping process (Fulghum, 1995; Imber-Black, 1988).

Furthermore, family ritual as a creative act has the potential to strengthen a family's ability to cope in a way that is uniquely inspired by the individuals and the challenges they face (Fulghum, 1995; Imber-Black, 1988). And, unlike many resources learned only through time and experience, family rituals can include the very young and are believed to benefit children who are two years of age or more (Pocock, 1997).

Reframing the experience of the illness and death of a child so that it has meaning challenges families to create and recreate memories, remember and share stories, and honour the child by

maintaining a connection to the child while going on without him or her (Clark, 1993). Ritual offers the opportunity to do exactly this.

This study seeks to describe and compare the manner in which two families practiced family ritual, and to identify pertinent implications and applications from their experiences. Because of the limited previous study of family ritual under such circumstances, a rich qualitative case study approach was selected for the collection of data. This method places emphasis on interaction between individuals, and recognizes that multiple meanings are possible (Holstein & Gubrium, 1994). These points are critical in a study involving family members whose coping styles and perspectives may vary. Context is also identified as being an important feature of the case study method because it is significant in determining the suitability of ritual in different situations, times, and family types (Holstein & Gubrium, 1994). Moreover, there is respect for creative representation and for a range of interpretations (Holstein & Gubrium, 1994).

Case study analysis has been used to determine what is unique and common in the experiences of the two participating families, whose use of ritual enabled them to both cope with and find meaning in the illness and death of a child.

# CHAPTER II

## Literature Review

As documented research is limited in its examination of the relationship between family ritual, coping, and meaning for families facing the loss of a child, the following literature review includes information that has been gathered and assimilated from these three different areas. By exploring the significant contributions made by ritual to the developing relationship between meaning and coping, this study incorporates each of these essential aspects, resulting in a more holistic and accurate understanding of the role of ritual in families coping with the death of a terminally ill child. Given this context, this chapter includes a detailed description of types and examples of family rituals. The role of ritual will then be examined, and finally, the concepts of coping and meaning will be further explored through the application of two relevant theories, Family Stress and Symbolic Interactionism.

### Types of Family Ritual

Wolin & Bennett (in Imber-Black, 1988, p.279-280), have categorized three types of family ritual according to the degree of structure they possess. These are family celebrations, family traditions, and patterned family interactions.

#### Family celebrations

Family celebrations demonstrate the most structure within the three categories and include rituals that can be recognized by the universality of their symbols. Family celebrations are usually

shaped by the more unique traditions observed within a family. They contribute to the family's sense of stability and connectedness. Examples include activities surrounding the high holidays such as Christmas and Chanukah, in which certain rituals and rites are typically observed; for instance, the selection and decoration of a tree, the lighting of the menorah candles, the preparation of special food, sharing gifts, taking time to appreciate life's blessings, and helping those who are less fortunate.

Family traditions

Family traditions, by contrast, are somewhat less structured, and take on a more unique form. With traditions, the observation of certain behaviours and activities will be continued from one generation to the next. Some traditions include passing down cultural and family folklore to new generations, and sharing talents and hobbies that the family identifies as being important to the preservation and continuity of their heritage. Passing on a valued skill such as fishing, knitting, or playing an instrument might become a tradition, particularly when keeping the skill in the family is the objective. These traditions are often a source of family pride and identity. Another example is the handing down of an object such as a prized heirloom as a reward for accomplishment or to mark the occasion of a family member reaching a specific life cycle stage. Doing things to strengthen family identity may also become traditions. Making every Sunday a day for being together and sharing a special meal can be considered examples of family traditions.

Patterned family interactions

Patterned family interactions are comparatively less deliberate and structured, and are the most variable of the different types of ritual. These are the most often performed and yet the least consciously observed. Patterned interactions also function to make family roles and responsibilities clearer. For instance, performing daily or weekly activities or chores together promotes family identity, duty, and commitment. Such activities might also include praying before meals, volunteering as a group for charity, and holding family meetings.

The boundaries between these three kinds of family ritual are flexible. For instance, as modern families explore their own spiritual and personal meanings of celebratory holidays, many find ways to challenge the practices of the mainstream culture, and create new traditions that reflect their changed values. Also, certain patterned interactions, such as household tasks, can be made relaxing and fun, and take on the form of a family tradition when repeated with some regularity. Gathering fallen autumn leaves every year may be seen as a collective chore or, conversely, as something to look forward to if children are allowed to participate by jumping into the collected piles and hiding in them, or if the family and their neighbours make a bonfire at the end of the season with all the leaves.

## Examples of Family Ritual

Examples of four meaningful rituals will be given to show how they may be useful to families facing the death of a child. These

rituals are described in a way that reflects the transition from life to death.

Celebratory rituals

Celebratory rituals include holidays and anniversaries such as birthdays. In cases where the death of a child is anticipated, as with a protracted terminal illness, some families will hold the child's upcoming birthday early to ensure that it is celebrated before he dies (Walsh & McGoldrick, 1991). This ritual allows special memories to be made and allows the family to redirect their energies into something creative. In so doing, the release of tension and stress is made possible (Scheff, 1979). When a child is dying, including him in the planning of his own party can help him feel that he is still able to contribute to the world around him (Walsh & McGoldrick, 1991). Continuing to honour birthdays following the death of the child may represent a celebration of that child's life.

By way of contrast, some families cease to acknowledge the life and death of a family member. Some even seem to have an unspoken rule that the deceased's name should not be mentioned (Fulghum, 1995). Some authors argue that avoidance of this kind prevents the progression of grief work and can have serious consequences in the long term (Fulghum, 1995; Clark, 1993). In the first year or so after their loss, families may find that continuing to celebrate the birthday of the dead child offers them the chance to remember him, to express their feelings about both his life and death, and to accept the loss that they have experienced (Walsh & McGoldrick, 1991).

Divestment rituals

Divestment rituals are frequently initiated by dying children, without any prompting or guidance by parents (Walsh & McGoldrick, 1991). The child may place importance in giving away belongings that hold special significance to her, and may feel secure in the knowledge that someone she loves will be the new owner and take care of the things that have been precious to her during her lifetime. For the child, this type of divestment ritual may demonstrate that she has come to terms with her mortality (Walsh & McGoldrick, 1991). For the family, it further stands as recognition that the family membership will soon alter (Fulghum, 1995).

The divestment of the child's belongings after she has died is usually a difficult task for families (Kohner & Henley, 1995). Going through the child's room, deciding what should be given or thrown away, and what should be saved as a keepsake can be a heart-wrenching experience. The family is the best judge of when they are ready to perform this kind of ritual. Many find that the passage of time makes the task easier. Following the child's death, the surviving family members may decide to preserve some of the divested belongings in a memory box (Fulghum, 1995). To this they may add personal items of symbolic significance. As the name suggests, this box serves to preserve a family's memories in ways that are both concrete and symbolic.

Mementos act as symbolic foci of strong emotion connecting the family to their feelings of love and loss (Imber-Black, 1988). They protect the memory of the child, and restore past events, words, and feelings almost as if they had just occurred (Benstein, 1997). Those

rituals performed around the time of the child's death help families to actualize the loss, to express their feelings, and to adjust (Fulghum, 1995).

Memorial rituals

Memorial rituals such as funerals or memorial services offer families the opportunity to express their feelings of love for the child. The ceremony serves as acknowledgment of the importance of the child's life and death, and as a focus for grief (Kohner & Henley, 1995). Many parents have reported that seeing their child's coffin made the loss real. "Immersing oneself in the predictable, familiar rhythms of funeral rituals provides a refuge. Order is imposed. People are present" (Kohner & Henley, 1995, p. 113).

Revival rituals

Revival rituals, also referred to as rituals of renewal, can take many forms in families. Acts embued with symbolism or meaning are often included in this category. Comfort may be taken from the idea that something creative or beautiful marks the child's existence. For example, creating a tribute such as the planting of a flowering tree or attaching a swing to a tree in the garden may enable the family to honour the child's memory in a way that is meaningful to them.

Other revival rituals may be even more meaningful, but they often develop internally and gradually. The aftermath of a child's death is a period of incredible transition and turmoil; yet, in time, personal upheaval may give way to personal growth. Healing and discovering a new meaning in existence is a lifelong ritual that is particularly important after a family has experienced the death of a

child. Moreover, it represents affirmation of both the child's life and life itself. But first, the family must address the challenge of finding or creating meaning from their tragic loss. Crossing the thresholds between life, death, and rebirth may lead to a spiritual transformation for families who have shared in this experience (Fulghum, 1995).

Some revival rituals are more private and informal in nature. Included are the more mundane habits and routines that provide order, structure, stability, and comfort. These rituals do not necessarily involve spoken words or observable actions. They are instead the passing moment at which the family is ready to move on, to renew their identity, and to begin life over again (Fulghum, 1995). In this way, "all our exits become entrances" (Fulghum, 1995, p. 232).

## The Role of Ritual

### Family needs met by ritual

Both academic and personal sources note that ritual meets the following essential family needs: 1) giving permission to meet one's own needs, 2) facilitating communication, 3) enhancing understanding, 4) reaffirming identity and belonging, 5) providing a secure environment for continuity and change, and 6) fostering family strength and closeness (McCubbin, et al., 1988).

### Meeting one's own needs

Some researchers have suggested that children be involved during the course of their sibling's illness and death. The degree of involvement is best determined by the family and the children

themselves (Martinson, 1994). However, it often happens that children's grief over the illness and loss of a brother or sister is overshadowed by the intense reaction of the parents (Walsh & McGoldrick, 1991). Thus surviving children are frequently forgotten and are left to grieve alone. Allowing children to participate in rituals such as funerals is a way of acknowledging and meeting their needs. When surviving children are left out, not only is their development at risk, but their ability to form healthy attachments later on in life may be seriously damaged by the family's inability to mourn and react to loss (Walsh & McGoldrick, 1991). During a child's final stages of terminal illness, the family may be very focused on him and his needs; rituals give the rest of the family permission to remember their own needs and to meet at least some of these (Imber-Black, 1988; Walsh & McGoldrick, 1991).

Issues of control may require resolution in order that individual needs be recognized. A sense of control is critical to families facing crisis, affecting their perceived and real abilities to cope. But control is not easily maintained when the life of a child is threatened or has ended (Blotcky, 1985; Walsh & McGoldrick, 1991; Korner, 1970). Rando (1986) identified "the power of acting out" as a property that allows families to do something constructive to overcome feelings of powerlessness that typically characterize the illness and death of a child; ritual serves as an appropriate outlet in this case. Within the family, members need to be able to control their own rituals; yet disagreement about what should and should not be done may force family members to address control issues when deciding which rituals to employ (Walsh & McGoldrick, 1991).

In addition, members should be enabled to make their own choices about ritual outside the family. When a child has been hospitalized for extensive periods prior to her death, many families become resentful of external or professional management of things that are deeply personal, and regret not having been able to say what they needed or wanted for the child and for themselves (Kohner & Henley, 1995). These circumstances may intensify the sense of helplessness that tends to develop both during the child's final stages of illness and in the aftermath of her death. Unresolved issues of this kind may re-emerge after the death of the child, as the structure of the family and needs of the surviving members change (Fulghum, 1995; Imber-Black, 1988). To counteract feelings of resentment, regret, and helplessness, families can engage in various rituals of their own choice and design.

Facilitating communication

Grief is an intensely personal and often lonely experience. Putting words to one's innermost feelings can prove painfully difficult (Benstein, 1997). But if the illness and death of the child are not spoken of within the family, then the remaining children may fear that the topic of their own death would be something that would go avoided and unrecognized (Walsh & McGoldrick, 1991). Because many family rituals involve and encourage communication, they are a wonderful medium for family members to become aware of such fears and misunderstandings. As rituals provide safe boundaries for self-expression, families can then talk about the issues surrounding terminal illness, death, and grief in such a way as to relieve the anxiety and stress that young children may be feeling (Imber-Black,

1988). While it may be difficult for some young members to articulate all that they feel, they should be able to participate in family rituals and draw meaning from them (Imber-Black, 1988; Pocock, 1997). Moreover, ritual links the surviving children to an emotional part of the parents that they may have grown afraid of losing (Imber-Black, 1988).

Enhancing understanding

Rituals contribute to family members' understanding and give their experience meaning (Fulghum, 1995; Imber-Black, 1988). This benefit is important, perhaps especially so for young children whose level of comprehension may prevent them from assessing illness, death, and grief in context (Walsh & McGoldrick, 1991). Allowing children to visit their brother or sister at the hospital, to be present at the memorial ceremony, matters not only at the time, but also contributes to their long-term understanding and acceptance.

To be permitted to see and shed tears of sorrow, frustration, helplessness, anger, and fear, rather than be sheltered from them, is important for siblings. Providing children with an environment where they feel safe to explore questions about what is happening helps them grieve as well. The implications attendant on a child's inability to grasp the reality of permanent loss are they may fear others will also leave them, that their family could dissolve, or they may become convinced that they too will soon grow sick and die.

Reaffirmation of identity and belonging

Rituals also satisfy the human need for inclusion by indicating family members' interest in family life and identification with the group (McCubbin, et al., 1988). Adopting, maintaining, or re-

establishing family ritual can renew a family's resiliency and commitment in troubled times (Fulghum, 1995; Imber-Black, 1988).

Ritual gives the dying child a chance to continue as a full-fledged member of the family. Terminally ill children tend to be aware of the disorganization their illness causes, and often feel guilty for the pain their family is feeling (Walsh & McGoldrick, 1991). Ritual enables them to feel that the family is fighting the illness together through the expressed unity of action, and helps to reduce some of the isolation that is experienced as part of dying. Rituals can also help the terminally ill child understand what is happening to him and help both him and his family to say good-bye. The final stages of a child's terminal illness are extremely emotional for the family as denial and hope disappear. The stark reality of the situation must be confronted, and ritual often provides the framework for needed courage. Ritual imposes order upon the emotional chaos. Although the family may feel helpless, ritual is a service they can still perform for their child. During the child's illness, rituals provide families special time for expressing deep emotions while also containing emotions that the family may feel are too strong to be exhibited elsewhere (Imber-Black, 1988). The same is true after the child has died.

> It is important that the bereaved person have a safe framework within which he can express all the feelings that are set in motion by the loss of the beloved. Rituals may meet the needs of the psyche at different levels by releasing the emotional responses that grow from group need and group support, that justify and accept deep feelings of pain without requiring explanation, all at a

> level below the threshold of consciousness (Feifel, 1959, p. 224).

Continuity and change

Several authors have noted the role that ritual plays in reaffirming identity and belonging for both the dying child and the other family members (Fulghum,1995; Walsh & McGoldrick, 1991). For example, bereaved families do not go back to being exactly as they were before the death of the child. Instead, they change as they integrate the loss into their lives (Martinson, 1994). Families commonly perceive changes in their values and priorities, in attitudes about death, and in the perception of control. They may also experience a loss of belief and innocence. As a result, family members may exhibit a maturity that is beyond their years; this is particularly true of surviving children.

Rituals are important in that they serve to preserve a sense of continuity which may be very reassuring to a family whose structure and identity have undergone change (Imber-Black, 1988). Following the change in family structure, rituals have an important part in realigning family roles (McCubbin, et al., 1988).

Rituals also give families the opportunity to maintain an emotional connection with the dead child in ways that are healthy (Clark, 1994). In fact, using ritual to create memories can actually facilitate grief work, as the following examples illustrate. Taking a private moment to collect one's thoughts, or to share favourite anecdotes with significant others, offers the opportunity for emotional release, and the opportunity to raise unresolved issues and lingering questions.

Following the child's death, ritual allows the family to return to the rest of the living community and resume their place in it (Fulghum, 1995). These elements of revival and renewal are integral to ritual. The relationship between the child and his surviving family may gradually evolve into one where physical loss is acknowledged while emotional and spiritual connections are sustained through memory and symbol (Clark, 1994). Ritual offers the means by which a bereaved family can "reach out to the dead child and feel the presence of the child within" (Benstein, 1997, p. 116).

Fostering family strength and closeness

Families may actually be strengthened by the stressors and strains of a crisis and become closer as a result of their shared experience with a child who is terminally ill or who has died (McCubbin, et al., 1988). Rituals can offer families opportunities to find the strength to face the last stages of the child's illness and the aftermath of his or her death (Imber-Black, 1988). For many families, being able to draw upon such strengths is critical during their time of crisis. This is particularly true for the dying child and his caregivers (Dickens, 1985; Walsh & McGoldrick, 1991). The use of family ritual is a reasonably reliable index of family integration – that is the ability to gain control, solve problems and handle crises (McCubbin, et al., 1988). While the form of ritual varies from family to family, it serves the same general purposes. Ritual further tends to develop such elements as predictable family and individual behaviour, social stability, and adaptability. Within families, ritual also enhances family management, cooperation, continuity, and pride,

while it decreases tension and conflict. Often, the very act of *doing* fosters a sense of control and structure (McCubbin, et al., 1988).

Each of the above considerations is significant in itself. Yet, when taken as a whole, they lend support to the value of ritual during both the terminal illness and the following death of a child.

## The Absence of Ritual

By way of contrast, some researchers claim that without rituals a family experiencing the terminal illness and death of a child may additionally suffer from: 1) poor coping and adaptation, 2) communication problems, and 3) feelings of isolation both within the family and in the larger community (McCubbin, et al., 1988).

### Difficulties in coping and adaptation

Grieving the death of a loved one is an important ritual and is essential for coping and adaptation to loss. Yet some family members may suppress their grief to make others more comfortable, or because they feel obligated to appear strong for the sake of the family (Benstein, 1997). Because an appropriate symbolic closure is necessary for the progression of grief work, failing to mark a child's life and death prevents families from grieving as they need (Rubin, 1996).

### Communication problems

An absence of ritual may also lead to such problems as a breakdown in communication (Imber-Black, 1988). Making terminal illness, death, and loss taboo subjects can have serious consequences such as prolonged depression and grief, potentially leading to

pathological behaviour and psychosomatic symptoms. This is particularly true for adolescents, because they are less likely than any other family member to attend counselling (Rando, 1986). While literature in the area of childhood terminal illness tends to concentrate on the experiences of young children and their parents, there is a particular need to address research questions to the entire family, and so include the important contributions of adolescents whose thoughts and feelings have not been well represented in the research.

Marital dissolution is another unfortunate consequence that is all too common in families who have lost a child due to terminal illness (Dickens, 1985; Walsh & McGoldrick, 1991). An estimated 50 to 70 percent of bereaved parents divorce (Klass, 1986). The sorrow, confusion, hopelessness, emptiness and despair that are experienced in grief can overwhelm parents, making being a supportive partner extremely difficult. Often adding to existing emotional pressures are different personal coping styles and strains on effective communication. Unspoken anger, blame, and guilt can build, causing additional tension which may ultimately lead to the break-up of the family (Walsh & McGoldrick, 1991). This may then result in loss of personal or family identity (LaRossa & Reitzes, 1993). Without the benefits of ritual as a facilitator of communication, the stresses and misunderstandings that form when feelings of loss are suppressed become harder to alleviate. Some of the more private rituals can help create deeper personal awareness, while those that are performed together provide moments for expressing one's innermost

thoughts and feelings (Fulghum, 1995). In time, this kind of sharing can allow couples to feel more connected to each other than ever.

Feelings of isolation

Rituals provide families with a sense of belonging at the same time that they are experiencing the illness and loss of a child (Walsh & McGoldrick, 1991). Without ritual, family members may feel less able to identify theirs as a healthy family (LaRossa & Reitzes, 1993). This problem caused by lack of ritual further adds to their sense of isolation from the rest of the community. Social isolation reduces the supports and other resources the family could potentially benefit from in their attempts to cope with grief.

## The Application of Theory

The role of theory is to guide research by providing a supportive conceptual framework. To conceptualize this study, I chose to use two theories, which seemed most relevant to my topic, Family Stress and Symbolic Interactionism theories. In keeping with the original research purpose, this choice was made to make less fragmented the understanding of the role of family ritual in how families cope with, and find meaning in, childhood terminal illness and death.

The relevance of Family Stress theory to this area is found in its assumptions about the shared meanings and definitions held by family members and about the importance of resources in coping and adapting to stress and crisis.

Symbolic Interactionism contributes to the relevant literature by supplementing assumptions about subjective meaning and

interpretation; and is, for this reason, particularly well suited to the case study approach chosen for this thesis.

Each theory has its strengths and limitations in its application to my topic, and each complements the other. Both theories will be discussed in their relation to the role of ritual in enhancing coping and meaning in families facing the loss of a terminally ill child.

## Review of Empirical Literature and Relevant Contributions from Family Stress Theory

### The importance of definition

Researchers have argued that the 'cognitive definition of events', 'appraisal', 'family meaning', or 'perception' of stressors and crisis is an important theoretical construct in the many descriptions of Family Stress theory (Boss, 1986; Hill, 1958; Koop & Keating, 1990; McCubbin, 1993; McCubbin, et al., 1988). Boss (1987) asserts that perception of a stressful or crisis event is a more critical indicator of a family's ability to cope than is the event itself. In the general Family Stress literature, how families appraise a stressful event or a series of events will determine whether it is a form of crisis or merely a form of stress (Boss, 186; Koop & Keating, 1990). Implicit in these assumptions are the ideas that families have expertise in their own affairs and that they can exercise a degree of mastery according to the meaning they attach to a situation. Herein lies tremendous potential for empowerment. Circumstances which may be seen as a crisis by people external to a situation may be defined by the family experiencing the events as a challenge that is within their control (Koop, 1994).

Most families who have experienced the terminal illness and death of a child claim their loss as the most devastating crisis they have ever endured (Walsh & McGoldrick, 1991). Family members can be brought to their lowest point emotionally by a child's illness and death, and they may search their hearts and souls for answers that bring comfort or solace. In their attempts to heal, families may find themselves more receptive to the task of discovering or creating their own meanings. Indeed, many people who share in this experience have declared that the coping process strengthened them, both individually and as a family (Klein, 1982). For these families, ritual may be defined as part of a coping repertoire which can help them when dealing with the stressors of childhood terminal illness and death.

And yet, a positive definition of family ritual will not necessarily be a part of every person's reality. Although family membership may engender a sense of group identity and belonging, a certain degree of independent thought is natural because different personalities are involved. Even when a family's perceptions and definitions are shared, it is likely that because of variations in adjustment time and skills, common perceptions and definitions will not evolve simultaneously for all members. The implications of this latter point are that cognitive appraisal may be quite different among family members, and that the members' experiences with coping in a crisis situation may vary according to their subjective definitions and to the timing of their appraisal. For those coping with the illness and death of a child, it is significant that family members may not all be at the same stage in the coping process (Kline, 1982;

Walsh & McGoldrick, 1991). Maintaining or initiating family rituals at times of heartbreak and crisis may be neither welcomed nor appreciated by the entire family unit. Some family members may discover that rituals provide a sense of hope in that they hold the promise of continuity, and that they place the experience of losing a child in context, thus giving the loss meaning (Walsh & McGoldrick, 1991). However, other family members may find that continuing or initiating rituals during the last stages of a child's terminal illness is artificial, and out of place (Imber-Black, 1988). Or, they may be required to invest more effort than they are able to, considering the tremendous demands already being placed upon their emotional and physical energy stores (Imber-Black, 1988).

The significance of resources

The availability and accessibility of resources to families facing problems or crises is another important construct in Family Stress theory. Resources are thought to be imperative for warding off a crisis during the build-up of stressor events, and to be equally important in coping and problem-solving processes for families in which crises have already occurred (Hill, 1958; Koop & Keating, 1990; McCubbin, 1993). The behavioral component of coping in this theory has been addressed by some researchers, who argue that resources must be identified as such by families (Boss, 1984; Hill, 1958). However, other Family Stress theorists concede that family members will not always be able to identify a beneficial quality, behaviour, or other resource as useful in a given context (McCubbin, 1993; McCubbin et al., 1986).

In families which have a terminally ill child or have lost a child, the loss cannot be changed; yet with access to needed resources, management of the crisis can be made easier and additional crises may be circumvented. Some may find that initiating or continuing rituals after the child has died is emotionally and spiritually healing because doing so helps them to preserve their memories of the child. Yet others may find such remembrances a reopening of wounds that are seemingly better left alone (Fulghum, 1995; Imber-Black, 1988). Understanding this distinction can help family members to avoid adding to existing pressures others in the family are experiencing.

Also consider the case that a family or particular members within the family have an inter- or intra-personal strength, but fail to recognize it as such. Or alternatively, that they feel this strength is a weakness. Indeed, under certain circumstances, this characteristic may well be seen as a flaw. However, given a particular context, the characteristic that has been defined as a weakness or that has never been defined at all, serves as a strength, a resource (Walsh & McGoldrick, 1991). The resource may help the family cope, maintain functionality, and become more resilient or closer. Still, they may not define this internal resource for what it is, or may ascribe their success in coping to a completely unrelated characteristic. For these reasons, researchers should question the necessity of cognitive appraisal; people have many strengths which they employ quite unknowingly. For example, it may be argued that denial, typically viewed as a pathological reaction to crises such as significant loss, actually has protective benefits when family

members are having to cope with more stress than they can effectively manage (Robinson, 1993; Russell, 1993). In this case, researchers are beginning to acknowledge that what has formerly been identified as a serious psychological problem (Rubin, 1993; Soloff, 1977) may be, at least in the short term, a healthy adaptive response.

Ritual as a resource

In this review, the role of ritual as a resource has been a major focus. If accessed by families, this resource can enhance coping and meaning for them. Researchers in the area of ritual refer to a "distancing paradigm" whereby catharsis is made possible through the ritual management of distress (Scheff, 1979). Three elements are necessary in order for management to be successful: 1) the evocation of distress - such as that which is caused by the terminal illness and death of a child, 2) a distancing device - in this case, whatever ritual(s) the family employs to facilitate hope during the coping process, 3) a discharge of distress - which may be either emotional release or denial (Scheff, 1979).

Family rituals can further contribute to the ability to cope by offering families the opportunity to affirm and improve their relationships (Walsh & McGoldrick, 1991). Yet engaging in rituals requires a certain amount of imagination, spontaneity, and enthusiasm, things which may hard to draw upon under the circumstances (Imber-Black, 1988). Moreover, individual personality differences within the family should be acknowledged. Some people are uncomfortable in a celebratory or ritualistic setting

(Scheff, 1979). The needs of the terminally ill child are important, and understandably often become the parents' primary concern, but this fact does not negate the importance of the needs of other members of the family (Walsh & McGoldrick, 1991). Where ritual is adopted, the input of all family members should be taken into account, not assumed.

Communication as a resource

Communication can be facilitated by family ritual, and is itself seen as an essential interpersonal resource among families who have a terminally ill child (Silberfeld, 1988). Researchers in the area of childhood terminal illness and death emphasize the point that feelings associated with loss and death should be openly expressed and explored as needed (Silberfeld, 1988; Walsh & McGoldrick, 1991). There are therapeutic benefits to talking about the situation as it unfolds both in the short and long term. Memories allow families to relive their experience. While this may be painful, it can be helpful and is part of grieving. The ritual of telling the story of the child's life and death is important and needs to be told to an understanding and supportive audience. Many grieving families feel that others discourage them from sharing their story because of their own discomfort with the topic of death and the display of grief. Some feel so pressured to find words that will bring solace that they avoid broaching the subject altogether. But finding the "right words" to say is unnecessary. What is important is that families be given the chance to express their feelings and that others be willing to

offer their time, their support, and their physical presence when these are sought (Benstein, 1997; Kohner & Henley, 1995).

That being said, there are times when family members may find articulating their worst fears or their pain anything but helpful (Imber-Black, 1988). And while some members may be ready to give their feelings voice, others may have not yet reached that stage. In such cases, feeling pressured into talking about the threatened or actual loss of a child may serve to increase rather than decrease stress among such individuals (Imber-Black, 1988).

An important objective of research in the area of childhood terminal illness is to find out whether or not the assumptions described above hold true.

## Review of Empirical Literature and Relevant Contributions from Symbolic Interactionist Theory

This discussion will now shift its attention to Symbolic Interactionism's assumptions about subjective definitions and meanings. The significance of personal meanings and definitions of the experience will be explored in order to enhance understanding in the area of coping with childhood terminal illness and death.

### Shared meaning

Symbolic Interactionists tend to assume that meanings develop as a result of human interaction (LaRossa & Reitzes, 1993). The foundation of meaning is believed to be in the imagination and perception, in symbols or shared interpretations that inspire a fairly uniform response among family members.

When applied to the issue of the role of ritual in terminal illness among children, this assumption implies that family members interact in ways that directly and indirectly create shared meaning (Bateson, 1979; Montgomery, 1988). Collective meaning about terminal illness is established through on-going verbal interaction between family members and the larger society (Silberfeld, 1981). Families whose perspectives have contributed to research have expressed that the crisis of losing a child is something from which they can learn, which has brought them closer together, and which has instilled in them greater empathy for others in trouble (Korner, 1970). Many bereaved families find that performing such acts as organ donation, establishing a scholarship fund in their child's memory, or volunteering their time and services for agencies like Ronald MacDonald House, established to help families with seriously ill children, makes their tragic loss meaningful.

Personal meaning

The Symbolic Interactionist perspective is also based on the idea that individuals act according to the meanings they attach to different aspects of their world (LaRossa & Reitzes, 1993). Perception, feeling, and action thus are seen as inseparable.

The significance of this assumption in the case of the role of ritual in families coping with childhood terminal illness and death is that related research must be sensitive to what meanings illness, death, loss, and grief have for people. These meanings may be quite different when the life threatened is that of a child (Walsh & McGoldrick, 1991). In addition, the special role of the primary

caregiver may involve unique meanings, which should be recognized (Judd, 1989; Walsh & McGoldrick, 1991). Particular awareness of personality differences, religious beliefs, and cultural contexts is also warranted (Druss, 1988). And because the setting of this study is the family system, gender and age differences merit consideration as well (LaRossa & Reitzes, 1993).

The relationship between symbol and personal meaning

Symbolic Interactionists emphasize the importance of shared and communicated meanings and symbols in how we make sense of the generalized other in relation to our interpretations of self, others, and our environment (Blumer cited in LaRossa & Reitzes, 1993). Symbols and symbolic actions are seen as the foundation of ritual (van der Hart cited in Imber-Black, 1988), and as such, make occasions of ritual more meaningful, sacred, and memorable to the family (Imber-Black, 1988; Fulghum, 1995). They are meant to include either actions or words, which offer the potential of altering beliefs, relationships, or the meaning of events (Imber-Black, 1988). Because symbols play such a central role, it is imperative that they be well suited to the family as a whole and to its individual members. Designing new rituals requires a search for appropriate symbols and symbolic acts for all family members (Fulghum, 1995). These symbols connect the family with the familiar and guide them through the unfamiliar (Scheff, 1979).

Furthermore, access to symbolic things which provide a dying child and his family with special meaning should be encouraged where possible in order to give comfort and to instil a sense of

renewed hope and strength (Silberfeld, 1981). Together, efforts to attach symbol to events occurring before and after the child's death may be instrumental in building an effective coping repertoire within the family. Rituals are valuable because they support the family in difficult times by combining the human needs for healing and celebration (Imber-Black, 1988). Symbols and images of hope can be sought in many places and then be incorporated into family celebrations (Jevne, 1994). In a variety of creative ways families can involve symbol and celebration to channel and buoy their strengths. Whether the family comes together to create a verbal or visual representation of ritual, the value is infinite, both for the process and its meaning.

The relationship between celebration and personal meaning

Children who are more actively involved with celebratory rituals tend to exhibit a greater understanding of what is happening in their family than children who have not had this benefit (Walsh & McGoldrick, 1991). Celebrating even the smallest milestones can contribute to new-found determination to live life to its fullest, and to making the time that remains available memorable and rewarding (Walsh & McGoldrick, 1991). Creating new family celebratory rituals or returning to abandoned ones can also enhance family closeness and unity (Fulghum, 1995). Achieving this level of appreciation may require learning to re-evaluate established attitudes and beliefs according to the demands and changes that characterize the final stages of terminal illness and mourning (Thomson, 1989). While holidays and other special occasions often increase in importance

when a child is terminally ill, they can be reduced to painful reminders following the child's death (Kohner & Henley, 1995). Anniversaries of events that took place before or during the illness can also evoke deep emotions (Kohner & Henley, 1995; Rubin, 1996). Similarly, attending events that the child likely would have participated in had he lived such as graduation and wedding ceremonies can be difficult for bereaved families. This may be the case even when the celebration centres around the family or one of its members. These kinds of events often trigger chronic sorrow[1], a normal response to the loss of a significant relationship characterized by recurrent episodes of grief (Eakes, Burke, & Hainsworth, 1998). Some families will abandon rituals for a while, or establish new traditions as they try to cope (Kohner & Henley, 1995). Initially the emptiness felt can be unbearable, yet in time these rituals may provide families needed opportunities to remember, to cry, to grieve (Fulghum, 1995; Imber-Black, 1988).

Subjective meaning

The Symbolic Interactionist approach establishes that subjective interpretation further enhances meaning (LaRossa & Reitzes, 1993). In this way, personally and socially constructed notions of reality emerge.

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Chronic sorrow entails periodic recurrence of permanent, pervasive grief-related feelings commonly associated with loss. Chronic sorrow has a cyclical nature, characterized by periods of happiness and renewed grief, which prevents grief from becoming incapacitating (Eakes, Burke, & Hainsworth, 1998).

The assumption this theory holds for the significance of subjective definitions of reality has important implications in the area of childhood terminal illness and death. In its emphasis on the subjective meanings families arrive at in coping with their experience, this approach allows family members to reframe their loss in a way that is meaningful to them (Hall, 1990). Viewing the child's terminal illness and death in a meaningful way enables families to cope with their situation.

Implicit in much of the existing literature is the suggestion that if children with terminal diagnoses profess a will to live or display high levels of hope, they are somehow not accepting reality (Thomson, 1989). This perspective assumes there is only one reality and that therefore, reality can only be objectively determined and defined. Further consideration of the distinction between realistic and unrealistic hope is warranted. Moreover, the question of whether or not hope is only beneficial if it is realistic should also be explored. The lack of consensus about this issue is a limitation of the literature. An advantage of Symbolic Interactionism's assumption of subjective interpretations is that it encourages individuals to create their own realities. This seems appropriate in a context which often forces families to make of life what they will.

Family identity and belonging

Symbolic Interactionists further assume that family identity is important. This point has special ramifications in my area of research. The impending loss of a child will alter the family structure and may potentially threaten the integrity of established

family boundaries (LaRossa & Reitzes, 1993). In the literature, this is referred to as boundary-ambiguity - a stressful problem that brings the issue of identity into serious question (Boss & Greenburg, 1984). Consider a family consisting of two parents or a single-parent and a child. If that child dies, who remains? A couple? A family? When a child loses its only sibling, is its status as brother or sister lost? The English language provides us with the words "orphan" and "widow" or "widower", yet we lack words to adequately express a parent's or sibling's relationship with a deceased child (Rando, 1986). In grieving multiple losses, it is not uncommon for bereaved families to feel robbed of role, status, and function. As roles change, bereaved family members may lose illusions of themselves. Reality may have once offered security, but can become plagued by questioning and uncertainty when a child dies. From this perspective it is not only the loss of the child that must be endured, but an unwelcome change in the surviving members' very definition of self as well. Family membership not only shapes our being, it provides us with a sense of belonging (LaRossa & Reitzes 1993). Who we are, and how we define ourselves in relation to our world, can be dramatically and irreparably altered due to the loss of a child (Benstein, 1997). The sense of isolation that terminal illness within the family can cause may be compounded by an absence of ritual, preventing the members from identifying theirs as a healthy family (Imber-Black, 1988).

How the conceptual framework complements the study

The strength of Symbolic Interactionism theory is its recognition that diverse meanings derived from perception and individual, group, and cultural contexts are valuable (LaRossa & Reitzes, 1993). How people redefine their experiences to make them more meaningful is also regarded as important (LaRossa & Reitzes, 1993). Symbolic Interaction theorists believe that behaviour is reflective of meanings ascribed to the phenomenon. These assumptions are primarily based on cognitive definition and subjective interpretation of symbolic meaning (LaRossa & Reitzes, 1993).

Family Stress theory focuses on cognitive processes as well, but places greater emphasis upon the behaviour inspired by such processes. The Family Stress perspective further assumes that internal and external resources, which are used to maximize the family's ability to cope, are essential to successful adaptation.

Whether identified as a cognitive or behavioral element, ritual has the potential to be a useful resource for families coping with childhood terminal illness and death. The distinction between collective and individual definitions is evident in the questions framed by the two theories.

In the development of good research, assumptions of family versus individual perception, feeling, and definition may be useful or problematic, depending on the context involved. The answer to whether meanings about the role of family ritual, illness, loss, and grief can be assumed to be shared is sought in this research.

Unfortunately, neither theory explicitly addresses emotional concerns, so it is left to the researcher to adapt the theories according to need and to circumstance. Where current theoretical constructs are inadequate, the researcher may propose new perspectives. This aspect of losing a child to terminal illness is absolutely fundamental in establishing a holistic perspective in research. If this gap in current theory were filled to supplement the assumptions from Family Stress and from Symbolic Interactionism, then researchers would witness the coming together of the essential elements of being: emotional, behavioral, and cognitive.

Together, the appreciation for family and individual meaning, interpretation, and definition that are articulated by Family Stress and Symbolic Interactionist theories provide the foundation for an integrated perspective for this study.

# CHAPTER III

## Method

In order to achieve an understanding of the role of family ritual in families coping with the terminal illness and death of a child, a case study comparison between two families who shared their experience was made. Open ended group interviews were held, yielding rich qualitative data. The taped interviews, a collection of poems, and other personal writing were analysed and presented as case studies.

### Sampling

Two cases were selected for the purposes of this study. Palys makes the claim that "A purposive choice will reflect our understanding of the phenomenon of interest, and hence may indirectly affirm rather than challenge that understanding" (1994, p. 147). However, when research, such as this study, is concerned with a variety of subjective perceptions and experiences, both unique and common elements are of value. The profound nature of human experience involves limitless potential for discovery; understanding its inherent depth is a worthwhile challenge.

Participants were notified of the study by poster and word of mouth. The Hope Foundation, Knox Metropolitan Church, the YWCA's Bereavement Services, and Compassionate Friends, a bereavement support group for families who have experienced the death of a child, were contacted and agreed to put up research notification posters to make an initial appeal to participants (Appendix A). Compassionate Friends, the Bereavement Society, and the Canadian

Cancer Society were willing to include an abbreviated version of this notice in their newsletters. This effort avoided the characteristically lengthy and arduous process of applying to hospital ethics committees for research approval to contact families who had experienced the death of a child.

Certain difficulties in obtaining a sample were encountered. As it was my hope to compare how family members cope with loss, I tried to find families in which all members would participate. It has been observed that men often cope with pain differently than women and that they tend to contain their grief rather than display it or discuss it openly. I found not only that some men were unwilling to participate, but that in some cases they discouraged their partners from doing so after their wives had previously agreed to be involved in the study. Understandably, the sensitive nature of this topic and the inclusion of children as participants did not make participation a popular choice. I anticipated that some parents might feel the subject of death is an inappropriate one for children to talk about and could therefore be wary of the idea of having their children involved in such a study. As a result, finding even a small sample of four or five families was not possible. Thus a case study design was chosen.

Of three families who showed an interest in participating, two were chosen to study as case examples. They were selected on the basis of their ability to meet the following requirements: 1) They were able to provide personal stories about how ritual was used in ways that helped them find meaning and cope with the terminal illness and subsequent death of a child in the family, 2) The deceased

child was under the age of thirteen at the time of his or her death, 3) The child died at least a year prior to the commencement of the study, 4) Where participation of the entire family could not be arranged, the involvement of at least one parent and one child was possible, 5) Two-parent, single-parent, and blended families were included provided that the family's membership had not altered since the child's illness, 6) Because this can be a difficult subject for the very young to talk about, surviving children under the age of seven were not included. Although I hoped to select cases that would provide diversity of family structure and experiences, it turned out that only two of the three families who volunteered fit the criteria, and so were chosen as the only ones available to me.

Furthermore, the participants were to be able to identify their family as one that had been able to attribute positive qualities to their experience, and were willing to discuss the role that ritual has had in fostering this interpretation. It was preferred that the children had not been afflicted with the same condition since certain illnesses may impose unique social or practical challenges that influence a family's use of ritual. I felt that the revelation of any such distinctions was important.

It was necessary that the family be accessible for up to two two-hour interviews, although it was not absolutely necessary for all members to be in attendance at both sessions, or to stay for as long as the interviews lasted. This allowance took into account the diverse schedules of older family members, and the short attention spans of younger ones. The families had to have a thorough

knowledge of the English language, as financial and time constraints of the researcher precluded the use of interpreters.

The first family experienced the death of a one-month-old infant fifteen years ago. Two unstructured, open-ended interviews were conducted involving both parents and their eighteen-year-old daughter. The advantage in selecting this family was that they had time to cope with, and reflect upon their loss. As a result, the dynamic and on-going element of ritual became apparent in the retelling of their story.

Inherent in the loss of such a young child are special considerations. Although the emotional ties that bond a family included the newborn baby, the family members interviewed were not afforded much time to get to know her before she died, the entirety of her short life was spent in a hospital ICU unit, and many of the moments families assume they will share together were simply not possible in this case. Originally I had only wanted to find families who had more time to get to know their child, to cope with the illness, and to respond to the diagnosis in order to compare how ritual is used before and after a child dies. However, this family had little time to adjust to the news that the baby was going to die, and were faced with medical crises on a daily basis. For this reason, coping through the use of ritual began for this family the day the baby died and in the weeks, months, and years to follow.

A second family of two surviving children and both parents also volunteered, although one of the children was unable to participate in the three-hour interview. Three years prior to the interview the middle child, a nine-year-old boy, died of cancer.

Compared with the first family, this family was able to share more time together before the child became ill, and after his diagnosis as well. The roles of the family members in relation to the child were likewise more established. However, as less time has passed since the boy's death, they have had less time to adapt to their losses, and as a result were at a different point in the coping process. This distinction invited interesting comparisons. This family incorporated ritual in meaningful ways, particularly around the time of the child's death.

## Procedures

### Data collection

Families who were interested in participating contacted the researcher by telephone. Once family members agreed to participate, one preliminary telephone interview with an adult member of each family was needed in order to assess whether the family met the inclusion criteria. As the researcher, it was my recognized obligation to provide an accurate description of the intended study, to offer complete anonymity, and to include any particular instructions that families needed to be aware of before they agreed to participate (Appendix B). Interviews were also arranged at this time.

Each interview took place at the family's home. After reviewing the written description of objectives with respondents and answering their questions and concerns about the study, the researcher asked them to read the informed-consent form appropriate to their age and then sign it (Appendix C). Parents were asked to sign for young children. One session of up to two hours in

length was needed in order to conduct the first interview. Included in the interview were questions about the family's background, about the child, her illness and death (Appendix D). At the initial telephone interview, the families were encouraged to bring a picture, memory box, poem or other symbolic item to facilitate their discussion. A second interview was conducted later with the first family to elaborate upon and confirm the findings of the first session. The same outcome was achieved with the second family by telephone. The follow-up interview was shorter in duration. This step not only allowed the stories to be told in detail, but also provided the opportunity to review what had been said before, and thus fill in any gaps in my previous interpretations.

A debriefing following the end of the interview was carried out so as to offer any additional information desired by the family members who had new concerns or interests related to the study, or to their participation.

In addition to data gathered from the interviews, I was shown family pictures and drawings, and was loaned a book written by one of the mothers about coping with the loss of her baby. However, the interviews served as my main source of information.

Unstructured group interviews

The unstructured interview was ideally suited for these case studies because it allowed complete stories to unfold. Furthermore, interviews of this kind afforded me a tremendous depth of detail which enhanced my work. The primary research strategy for data collection was to conduct group interviews with all participating

family members in order to better understand the perceptions of all members. The family unit is a collective group, and has established dynamics to be taken into consideration. Parents often think that they know their children so well that they can answer for them, or do so in an effort to protect them. This tendency was discouraged, thus allowing the entire family to contribute to the discussion, and to express their feelings about the illness and loss of the child. While I strongly felt that the final work would be more balanced if all voices were represented, achieving this goal was a challenge. Engaging the younger family members was not always easy. Interviewing the families once more aided in the development of rapport in this case. Conducting a second interview also noticeably improved the quality of results. I found it helpful to review the interviews the day after they had been taped, to journal my reflections, and to alter my next interview accordingly.

## Ethical Concerns

### The issue of harm

Ethical issues are particularly important in an inquiry that deals with such a sensitive matter as this (Denzin & Lincoln, 1994). Participants are at a certain risk of being emotionally harmed by the interview process. For my participants' protection, my study was subject to the approval of the Ethics Committee of the Faculty of Agriculture, Forestry, and Home Economics at the University of Alberta.

Awareness of the risks of potential harm to the participants was therefore instrumental in guiding the researcher's choice of interview questions (Fontana & Frey, 1994). It was my

responsibility to minimize these risks and to try to ensure that the interview experience was positive for those involved. As a researcher I fully understood and was committed to securing the participants' rights to dignity and well-being; first and foremost I was accountable to my participants. Particular attention was paid to the emotional reactions of the family members whose needs took priority during the interview process. On occasions when certain details brought family members to tears I asked if they felt we should stop the interview for a while. My participants found this unnecessary, and expressed that they were glad for opportunities to show what they felt. There were times when redirecting questions to other members or shifting the line of questioning to something more neutral was appropriate.

Unfortunately, emotional harm can be done inadvertently. As this study was sensitive in nature, it brought out strong emotions. (Fontana & Frey, 1994). In this case, it was incumbent upon me to predict such reactions, and to be prepared to supply my participants with relevant information about informal and formal resources that are available. I gave a list of resources related to crisis and bereavement to the participating families (Appendix E). I recognized that I was not in a position to give counsel to families and maintained the researcher role (Denzin & Lincoln, 1994). Fortunately, the families chosen for this research project already had the benefit of support group membership and private counselling, and were therefore in this sense provided for.

Potential benefits of participation

It should be recognized that most participants who have been involved in research concerning the loss of a child regard the interview experience as positive, even cathartic (Judd, 1989). In fact, for those whose stories are filled with pain, many report that being given the opportunity to be heard was therapeutic and, in the long run, important to the healing process. In the area of childhood terminal illness and death, many families report that their participation in qualitative research studies empowered them by giving them the opportunity to increase awareness and understanding of their experience. The chance to help others allay their fears and reduce their sense of isolation offers families a sense of purpose (Kohner & Henley, 1997). Through the medium of the interview, they are able to explore the meaning of the illness to them, and to regain a sense of self-mastery and strength in looking back at how they coped with crisis. Telling the story allows families to recount times spent together. "It was as if I needed her life to be given recognition, and confirmation that the aching love I felt belonged to someone who really existed" (Rubin, 1996, p. 126).

The story-telling process, which is in itself a traditional ritual, also increases the self-awareness of participants and makes them more sensitive to the needs and feelings of their fellow family members. And what is more, talking about the experience of loss enables a healthy expression of grief and tends to make the situation more real. Discussing family rituals in this context can bring back positive memories that contributed to the family's sense of strength, and may renew that sense for them as they continue through the

coping process. Those whose lives are forever touched by the experience of a child's terminal illness and death, and those who dedicate themselves to helping them, can benefit from stories of how other families have found closeness, strength, and hope when surrounded by sadness and pain. And most importantly, the telling of the story allows families to remember that their journey was made together. This is perhaps the most significant contribution of ritual for families coping with the loss of a child. While this research is not intended to act as a form of therapy, my wish was to help families, and if this is one of the less formal consequences, then the research will be all the more worthwhile.

## Anonymity

In recognition of the participants' rights to anonymity, I offered to use pseudonyms in place of their real names. However, both families felt strongly that their experience would lose its poignancy if it were not represented as theirs. For this reason, the family members requested that their names be left unaltered.

The interviews were taped and then transcribed at a later time. All tapes collected for the purposes of this research will be destroyed five years after the project is completed, but the transcripts will be retained.

## Data Analysis

Qualitative research appreciates that multiple meanings can exist - an idea which honours how family members collectively and individually are affected by their relationship with a terminally ill child (Denzin & Lincoln, 1994). The emphasis on interaction between

individuals is well suited to a subject whose primary objective is to examine family experiences. Moreover, this perspective recognizes that the researcher is an integral part of her work and that her analysis is necessarily very subjective in nature because of her presence. Meaning and truth were personally constructed through my analysis allowing for creative interpretation and representation. Moreover, the attention to detail accorded by the case study method is ideal for the purposes of revealing the depth and resiliency of the spirit.

Use of the case study method

The case study was selected for my approach to the topic for several reasons. The role of ritual in the coping process and the development of meaning were of primary concern to me. Case study analysis emphasizes complex contextual factors and issues, relying on descriptive evidence. As my interviews contained tremendous detail, the choice seemed apt, and because the stories were so distinctive, I felt a comparison between the two was warranted.

Analysis served to find that which was common and that which was unique in the experience of how families use ritual to find meaning and cope with the terminal illness and death of a child. Both have value in this research.

Before identifying underlying themes within each case, it was helpful to review each interview in its entirety. It became apparent at this time that some data were not helpful for category formation and should be disregarded. Excessive background information comprised the majority of what was unused. Yet for the most part

the responses were focused. The data used were chosen according to their congruency with the research question and to their availability. However, significant themes were explored whether or not they upheld my questions and assumptions. I chose to focus on a few major issues which I felt offered the most valuable contribution to the understanding of my topic.

In keeping with case study guidelines, the context, detail and the way language was used to tell the stories were preserved in such a way as to be truly representative of the voices of each participant. This point had special significance because the subjective definitions and meanings of the participants influenced my analysis.

Categories were formed according to common themes that emerged from the data rather than being imposed upon it with the recognition that "the contexts of interpretation are themselves ongoing accomplishments, reflexively supplying meaning to actions and objects as those meanings maintain, elaborate, or alter the circumstances in which they occur" (Garfinkel, 1967; Heritage, 1984 in Holstein & Gubrium, 1994, p.266). The identification of recurring themes was subject to my own subjective interpretation (Denzin & Lincoln, 1994). For this reason, it was necessary that analysis should include continual exploration of research and personal assumptions. Meaning was then derived from the descriptions of my participants. Journaling allowed me to document the evolution of my thoughts and impressions as the study proceeded. In this way, observational, methodological, theoretical, and personal issues that arose were voiced and worked through (Denzin & Lincoln, 1994). Questions also

developed that were left unanswered by the research. These too were included in the final analysis.

In representing data, I offered my own interpretation of the essence of families' personally held meanings and then compared my condensed version to the original stories (Huberman & Miles, 1994). Thus data analysis was an on-going process of reflection, interpretation, and re-interpretation (Denzin & Lincoln, 1994). By including "written accounts contain[ing] a high degree of internal coherence, plausibility, and correspondence to what readers recognize as their own experiences authenticity and quality of the research could be ensured (Atkinson cited in Lincoln & Denzin, 1990, p. 381). It was, therefore, my hope that the final product recreate the participants' experiences in such a way that they become real to the reader.

Rigor

The outcome of a case study may be judged successful if rather than proving the validity of the research argument, it supports it (Stake, 1994). I achieved this goal by making the case studies as detailed and complete as I could and by representing the voices of my participants in an accurate manner. The realization of this initiative was also made possible by examining the coherence of other sources of data - the poems and writing of my participants, and by the investigation and analysis of two distinct theories to support my findings. The involvement of multiple family members also served to verify the ideas put forth. Once my findings were complete, I discussed them with a secondary informant, one of the

organizers of Compassionate Friends who agreed that my summary of interpretations was reflective of the experience of most members. This corroboration assured me of the accuracy of my findings. Confirmability was further made possible by reviewing my field notes written the day after the interviews were held and my journal entries that I made throughout my investigation. To strengthen the arguments I made, I also examined the consistency of the interpretations I was making with the perspectives of my participants, and challenged myself to consider alternative possibilities. Thus the research question was approached from different directions, thereby enhancing the finished product.

Credibility

Ultimately, being true to the lived experiences of the participants and preserving their voice is the essential test of credibility in the interpretivist analysis technique (Denzin, 1994). By keeping my objectives in mind and by nurturing feelings of respect, interest, and appreciation for my participants, standards of integrity in research could be achieved while preserving the voices of those whose stories are included (Fontana & Frey, 1994). Consistency between the descriptions of participating families and the interpretations of the researcher served as evidence of credibility. The data can be considered reliable if the participants confirm the findings as being reflective of their experience.

Generalizability

It should be noted that the empiricist emphasis on generalizability does not always apply in case study analysis. This matter may be irrelevant to a form that relies so greatly upon meaning and interpretation (Stake, 1994). The merit of this kind of analysis is its uniquely personal exploration of phenomena. Therefore, in this context, credibility cannot necessarily be determined by replicability. In identifying themes, the level of specificity warranted particular attention. While specificity is valuable to the creation of rich and distinctive representation, categorization that is too specific can limit application of the findings (Holstein & Gubrium, 1994).

## Delimitations

Changes in the meaning, purpose, and nature of ritual from the later stages of illness to the aftermath of the child's death were examined in this thesis. For this reason children who have died unexpectedly were not included. It is recognized that some elements of loss of a child due to chronic and acute illness, accidental death, suicide, and murder may be comparable to those of terminal illness, however, this researcher maintains that there is sufficient difference to justify a distinction.

Because it was my intention to compare stories of how ritual was used and what meaning it held before and after the death of the child, the focus of the study was on families in which a child has died. Yet the findings may have applicability to families in which a terminally ill child is still living.

It should be recognized that there are some unique factors involved in the loss of a baby that distinguish it from the experience of losing an older child. There are also some that are common. Both received attention here.

I chose to approach the loss of a child as an event that could include any minor children. Indeed families who have coped with the loss of a child may identify with the accounts of other bereaved families - yet each story will stand apart. I recognize that this fact may draw criticism of the method or sample selected. However, the potential to express meaning, to explore the benefits of ritual, and the example of successful coping with loss are seen as elements that can be shared. While families with older terminally ill members can benefit from the use of ritual, it is felt that this topic has already received some attention in research (Fulghum, 1995; Imber-Black, 1988). Moreover, it was beyond the scope of this study to include the entire realm of related experience.

## Reaching Research Objectives

The success of this qualitative study can be measured by its contribution to current knowledge in the area of childhood terminal illness. Knowledge is inherently incomplete (Denzin, 1994), yet the research should significantly contribute to what is already understood. But the results, in themselves, are limited if they cannot be applied in a meaningful way. Therefore, the information that emerges from this research may be regarded as worthwhile only insofar as it is useful and empowering. The research may be deemed successful if it challenged the status quo, or inspired families,

theorists, researchers, or even some of these to look at the role of family ritual in the enhancement of meaning and coping in grieving the loss of a child in a different way, that is, one that is more positive.

# CHAPTER IV

## Findings

### Introduction

This chapter introduces the Michauds and the Roaches to the reader and then explores the structured and unstructured rituals the two families have employed as a means of finding meaning and coping with the death of a terminally ill child. Because there appeared to be a blending of themes in some cases, but not in others, the families' stories are presented together or separately as seemed appropriate to each section. As part of my original intention in this research was to examine the role of ritual in families coping with the terminal illness as well as the death of a child, I have included an additional section in this chapter, focusing solely upon rituals performed by the Michaud family before Adrien died that included him. The rituals are organized according to the following themes which emerged from our discussions: telling the story of Adrien's and Lindsay's life and death, preserving the connection to the deceased child through finding meaning, and making a tribute in the child's memory.

It is my purpose here to introduce to the reader the two families who shared their stories, and to describe some of the challenges the members faced together: the medical crises, stress, and loss of dreams. My personal reflections are interspersed throughout, and while it can be hard to adequately express the depths of loss in writing, the family members' own words are offered throughout to texture and convey some of what they experienced.

***

*"I'll love you forever, I'll like you for always. As long as I'm living, my baby you'll be." (Robert Munsch, 1986)*

## "I Never Got to Hold Her"

When I first began thinking about what role ritual might have in helping families cope with the death of a child, the significance of those rituals that go unobserved did not immediately occur to me. The force of this latter idea most strongly presented itself early in my conversation with the Roaches. How would it feel to bring a child into the world and never have the chance to hold her? To never take her home? To miss all those 'firsts' which parents anticipate and celebrate? To anxiously await the day a little sister is welcomed into the family, only to find that she cannot stay and that others will deny or minimize her brief existence? To return home from the hospital and pass an empty room that had been furnished and decorated as a nursery? These questions relating to lost dreams and unobserved rituals guided my thoughts in the following section.

The Roach family live in a small community in rural central Alberta. Corry is wife, mother, and nurse. Gene is husband, father, and forester. Their eldest daughter Brandi is now nineteen, and has moved to Edmonton where she attends college.

Their story began fifteen years ago and focused upon a very small someone who had a very big impact on the lives she touched. Lindsay was their newborn baby girl who fought for life for 26 days before she died.

The youngest child, David did not participate in the interview as he had been adopted after Lindsay's death. I found the family

comfortable and close. Their relationship was warm. They invited me into their home and shared with me the story of the baby's short life and death.

Corry's sixth pregnancy proved complicated and risky. In the three years following the arrival of their firstborn, the couple endured four miscarriages. So as a precautionary measure, Corry spent much of the eight months in hospital where her fluctuating condition could best be monitored, and her baby had a better chance of being brought to term. On August 25, 1983, 34 weeks into her pregnancy, Corry gave birth to Lindsay Erin Roach by Caesarian section. Although somewhat premature, the newborn weighed an encouraging 4 pounds, 6 ounces. She was a tiny, pale bundle with plenty of dark hair.

Lost dreams

I wanted to get a sense of what the family's dreams for this child had been and, in facing an extremely different reality, what it meant not having those dreams fulfilled.

> Corry - The hopes and the expectations...Oh my God! Well I don't think any child could have been more wanted. I spent the majority of the pregnancy in the hospital with intravenouses first in my arms and then in my legs until I had no veins left. And trying to grow this baby big enough. I lost fifty pounds from the time that I got pregnant to the time I delivered. The dreams that we had...well to have a normal family to have the white picket fence. To have someone for Brandi to play with, someone to be a big sister to. When she was little she always said, "Can I buy a sister? I need one so badly".

> Gene - I don't think I had any expectations. Just healthy and let's get back to normal. Because we'd spent the whole pregnancy from hospital to home and Corry was in hospital for three days one week, and then the next week she was in it for two weeks, then home for four days, and back for a week, and it was just crazy. By the time she had the C-section there was no energy left. We were already sucked dry.

Medical and personal crises

While the pregnancy itself had been considered in jeopardy, it was believed that the baby would be fine. However, her initial post-natal examination revealed that Lindsay was having trouble - her blood would not clot normally. The infant had an inherited bleeding disorder. Her doctors, suspecting she was septic, performed surgery on her the day of her birth and found that she was bleeding into her abdomen. They drained the blood and put in a respirator to make breathing easier for Lindsay, but the machine blew a hole through her lung. Additionally, she was in almost complete renal failure her entire life. It was later discovered in her autopsy that she also had biliary fibre throughout her kidneys, interfering with their ability to function. Lindsay's chances were poor. Corry recalled, "The doctors didn't expect her to live for 24 hours, but she lived for 26 days."

Circumstances challenged the family to concentrate their energies on how to face the horrible news that Lindsay would die. But coping would be a formidable challenge; that energy had to come from somewhere.

> Gene - It was so much in the moment with what we were going through. It was like we were on borrowed time for the whole eight months of the pregnancy. I always felt

> that by the time Corry delivered we had no energy to deal with the new crisis. I think that's one reason that it devastated us so badly - there was nothing left. There was no gas physically or emotionally - we were all just exhausted. And then we had to start the real crisis. Everything before she delivered had just been a worry.

After Lindsay was born Corry should have been recovering from her difficult pregnancy and surgery, but instead she and her husband had to contend with physical exhaustion and enormous emotional pressure. Under these conditions, they found supporting each other virtually impossible.

> Corry - I remember one day at home Gene collapsing on his knees in front of me And he put his head against my chest and I thought, "Oh no! How am I going to help him? I have nothing to give him". And I remember putting my head down and not being able to see because the tears were blurring up and then watching the tears fall on top of his head. And all we could was hold one another...but at least we could do that.

In the Neonatal Intensive Care Unit, Lindsay lay in an incubator connected to tubes and machinery for her life support. Her father was the only family member to see Lindsay before the connections were made. But Brandi was not made uncomfortable by the sight of foreign medical apparatus. As a child, then of only four, her simple, honest expectations and perceptions in this situation served as a remarkable contrast to those an adult might hold.

> Brandi - I remember putting on the hospital gowns and scrubbing with the big scrub brush and soap and going in. I couldn't touch her with my skin because she was in an

> incubator so I could just put my hand through the hole, but I couldn't touch her. I remember she didn't look sick.
>
> Corry - Brandi said, "Oh look! That's my sister. She's in her nakeds and she has a girl tush and it's just like mine so that must mean she's my sister." And then she asked if she could kiss her hand and I thought isn't that typical for a child...she asked to see her sister and that's what she saw.

For many parents the responsibility of "making it all better" is deeply ingrained. It's hard to accept that sometimes we can't meet the expectations we have for ourselves and those that our children have of us. When the role of protector is so much a part of one's identity, it can be harder still to reconcile oneself to the sense of having failing one's own parental expectations.

Gene and Corry struggled with wanting desperately for their baby girl to live and wanting her pain to end. When one surgery after the other was proposed for their infant daughter, hope became displaced by despair. Gene and Corry felt helpless as their dreams for Lindsay fell apart. Gene remembered saying, "I just want to take her home. I don't want to go through this. I just want to take her home, that's all I want to do".

Losing Lindsay

Eventually, when it became apparent that Lindsay's only brain activity was being caused by seizures, yet another invasive procedure was recommended. The Roaches' protests were challenged, but then the matter was decided. Lindsay died. Again emotions were intense but conflicting. The Roaches felt tremendous

pain in their loss, but also relief for their baby's release from suffering.

So many of milestones would never be celebrated with this child, but what of the smaller events most families naturally share? The Roaches were never allowed to hold Lindsay before she died. Corry said, "The only memory I have is holding a dead baby." For her, being able to do at least that provided some compensation, some comfort. But as a mother, Corry regretted the missed opportunities.

> Corry - Families should be enabled to do what they feel they need to do to be at peace. So no matter what the outcome is, no matter what happens, you know that you did everything that you needed and wanted and possibly could. And you can be completely at peace knowing exactly that. So often people live with regret. For me it was the most simple things. I didn't know that I would be allowed to wash the baby, for example. I didn't know that I was allowed to dress her or keep a lock of her hair. I didn't do any of those things which are just a part of a job to someone else but for a parent, something so incredibly sacred.

Because Brandi was only four years old, some of her memories of this painful time were confused and perhaps became more obscure over the years.

> Brandi - I remember initially after she had died I thought she was coming back or maybe there was something I could do to make her come back. But I don't ever remember her being sick. I only remember my mom being pregnant and then Lindsay was born and I visited her, and then she was gone. And I didn't know where she went. I didn't really understand, people explained it to me but I didn't really get it.

Ultimately, all that the Roaches lost in Lindsay's dying was difficult even for the adults to understand, and the passage of time does not always make things easier.

> Gene - It's like you touch a stone (i.e. Lindsay's gravestone) and it's still not real, it's just not real. It can't be. It's your daughter. But you can't help thinking, it can't be my daughter. This doesn't...it still doesn't make sense sometimes.

Capturing memories

For families who experience the loss of a young baby, the major milestones other than birth cannot be looked back upon. Instead the briefest of bitter-sweet moments are clutched and preserved in memory.

> Corry - I remember when she was dying, putting my cheek on her chest and feeling that thready heart beat against my cheek and asking God to ingrain that in my soul so I'd always remember that, no matter what happened. And it's funny, the roses on the outside and that thready heartbeat is on the inside.
>
> And I can't even begin to put words to what that means because it goes so deep. It's an amazing kid, an amazing kid, to be only a month old and so tiny and so strong.

***

"He Was My Farmer, My Dreams"

Darlene, Gerald, Gabriel, Desirée, and Adrien were a French Canadian farm family with traditional values and a strong sense of togetherness. Darlene is a homemaker, wife and mother, Gerald a welder and mechanic, and Desirée a fourteen year old junior high

school student. They were present at the interview. However, the eldest child, Gabriel, was unable to participate.

The focus of our discussion was Adrien, the youngest of the three children. In many ways he was a typical eight-year old boy: active, agile, and willing to take risks. Beyond his energetic enthusiasm for life, Adrien was described as being warm and affectionate. He possessed a unique brand of humour and a sympathetic understanding of what those around him felt and needed. He was a child who would share everything he had.

Medical crises and personal challenges

In July of 1994, it was found that a brain-stem tumour was the cause of some recently observed changes in Adrien's coordination and behaviour. Within hours of the initial diagnosis, Adrien's parents were informed that his prognosis was terminal. During the next eight months, he endured radiation and steroid treatments. He suffered from temporary paralysis, impaired vision and motor coordination, personality shifts, and finally, a collapsed lung and Spinal Meningitis.

The family faced several challenges as Adrien's illness progressed. There were long periods of separation for Adrien and his mother from the rest of the family. This change forced a new kind of independence upon the children and their parents. Gabriel and Desirée matured quickly, assuming some tasks normally done by their mother. And there was a blending of roles by husband and wife as Gerald took on more responsibility for household and childcare duties, while Darlene had to learn to drive and find her

way in a city which was unfamiliar to her as part of her adjustment to being isolated from the support of family and friends.

Gabriel and Desirée missed their mother and they longed for the chance to spend more time with Adrien. Yet, seeing their brother so sick and so changed was painful.

> Desirée - It was like meeting a whole new person. Because I wasn't always there I couldn't get used to it. But when I would see him it was kind of like, "No, that's not him." But it was just weird because one day he would be all happy and O.K. and the next day he got sick and tired and sleepy and sad and the change was just...I don't know, weird.
>
> But if we could go back to that time, I'd probably have stayed there the whole time, even though it would have been harder. I would probably understand my mother more. And I'd understand the whole thing more because I didn't really get to see it. I just saw what they wanted me to see sort of thing. I felt kind of left out because I was really, really close to my Mom and for eight months I couldn't be because she was always with my brother. It seemed like she never was with me because she couldn't be.

The family chose to be honest with Adrien about what was wrong with him and to help him understand. But understanding and accepting do not always walk hand in hand. In response to his parents' explanation Adrien emphatically replied: "O.K., but I'm not going to die like Grandpa did."

> Darlene - And he believed that, we were hoping, we believed that too, because what choice do you have? And only once did he say to me, "I don't want to die, Mom."

Holding on

As a child approaching the end of his life, Adrien was engaged in an intense emotional and physical battle. He had to adjust to tremendous change in his abilities, and there were times when his trials took a toll on how he related to his family. When he wasn't able to lift his family's spirits, they rallied around him to restore his good nature.

> Darlene - Desirée was really good. She liked to help all the time and what was really weird was he got really angry with his Dad and his brother, he wouldn't let Gabie do nothing for him. Desirée could do whatever she wanted, and she would read him stories and stuff, but Gabie, he didn't want anything to do with Gabie. He got very angry with Gabie and I used to give him heck for that and say, "Listen, Gabie is trying as hard as he can. He loves you and he wants to help you so you've got to quit this. This is garbage."
>
> So after a while, near the end, he would let Gabie help me 'cause I couldn't pick him up a lot of times. And when he was having a bath, Gabie would help me bathe him. But he was angry probably with the two people that he loved the most, and they say that happens a lot. Which is too bad 'cause it wasn't acceptable for anybody to be mean. After all, it was nobody's fault, it was just something that happened. And, I mean, I didn't care if he got mad at me or whatever, that is fine. But his sister and brother were different; they were having a hard enough time coping.

Sometimes when life's challenges steal all our strengths, a mask of courage is all that we find left to reach for. The Michauds found that sometimes this pretence has to be enough.

> Darlene - I'll be honest with you, he cried once. Adrien was trying to hide a lot of stuff from me. He cried once

> and that was when he was walking. He got up and walked again, which they were quite surprised at. After his radiation he was starting to get everything back again and he cried once when he looked in the mirror and saw he was fat. He didn't realize that he was now 85 pounds and he was very round. That's when he cried and realized that things weren't normal. That's the only time he every cried about it. He always trusted that we would make the right decisions, but he never liked me to leave him alone, never.

The family found comfort in each other and together faced the remaining days of Adrien's life. Gerald and Darlene took whatever opportunities presented themselves to try to help Adrien accept his situation, a formidable task for parents when they have their own struggle of coming to terms with what lies ahead for their child.

> Darlene - We took Adrien for a sleigh ride, and he fell off and he just stood there, and I said, "Well, what are you waiting for?" "Well, I don't know" he said. And he was really sad 'cause I think that was the next time we had talked about death and I said, "You know, Adrien, you can sit here and pout about it all you like, but if I was you I would enjoy every moment. You might as well live every day before this, Adrien, and take it as you can because I don't know what's going to happen to me, and I don't know what's going to happen to you. I know we all die, but either you enjoy life for what it is while you can or you don't. But don't sit here and pout about it because it's not going to do you any good." And he got up and he ran and jumped on the sleigh and he was off again.

Letting go

Families may equip themselves mentally before the death of a terminally ill child, and they may have considerable knowledge about what to expect at their disposal, they may even have

experienced the loss of the child in dreams. Yet the actual event of the child's death is something they can never be fully emotionally prepared for.

> Darlene - The social worker explained what was going to happen to Adrien now and what we could take off of him. And about two weeks before he died they had asked us if they could put a "no code" on him. And that was probably hardest decision we had to make. We said yes. I remember Gabie being upset...
>
> Gerald - Yeah, it wasn't an easy decision.

Losing Adrien

> Darlene - But the last weeks were just horrible. Near the end I knew he wasn't swallowing any more, he wasn't eating like he was. And the Saturday before he died we went out for supper and Gerald brought me home to get some rest and to discuss what our options were. Then I went back to the hospital.
>
> Adrien had been asleep all day and he never woke up while I was gone. And this was at ten o'clock at night and I was trying to wake him up and I can remember you were sitting on the window thinking, just giving me just a blank look, and I knew that if I didn't wake him up he wasn't going to wake up. I just knew this because I had spent so much time with him. And I knew that if he slipped into a coma that was it. I was panicked and I was trying to wake him up and he wouldn't wake up. So you stayed with me that night and he woke up early in the morning. You had heard him wake up. But I was just, whoah! I wasn't ready for him to die a week before he did, I just wasn't.

It would be harder for Darlene to return home without Adrien after his death, while the rest of the family had had to adjust to

going home without Adrien for weeks. But conversely, Darlene had spent so much time with her son during his illness that letting go was a more gradual process, whereas for the rest of the family the transition was far more abrupt.

> Darlene - The next morning, Gerald came and then they moved us up into our own room and they turned the power and the sound off the monitors. No, actually, we spent the night with him after that. You came in and I slept with Adrien that night. I can remember his body being hot and cold, but you know that was probably one of the first nights I slept, which was really a change, but I guess I kind of figured it was coming. And then in the morning we got up and his breathing was getting worse and I ran to go to the bathroom in the morning and when I got out of the bathroom and I noticed Adrien's breathing and they said, "Just watch his breathing and it will get funny and it will sort of stop." So I crawled up on bed with him and I was holding him. And you were on the phone to Doris, telling her it wasn't going to be much longer. And then Adrien sort of gave his last breath and Gerald had a face-cloth so we wiped his mouth. Before he died they had put a...well, it looked like a little pig nose, but it was to keep his tongue back. So before he died I pulled that out of his mouth. Gerald wiped him up and then we held him. I told you to let him go. Adrien was hangin' in there and I said to Gerald, "Tell him he can go home now." Do you remember me telling you that? I said, "You have to let him go."
>
> I'd already let him go, I had no choice, but for me I lived with him, I'd seen what was going on every day. The last week was downhill and a lot of things were happening and I knew it was coming. So I had sort of braced myself for it, and in some ways, I don't know how, maybe because my Dad had died three years before. He had sort of prepared me in certain ways, and I can't explain it, but he had. So when it was time to let Adrien go, I had let him go, I said good-bye to him. I had to tell Gerald to let him go because Adrien was fighting so hard and I knew all he needed was for his Dad to tell him it

was O.K. And then once you did he died. And as I was holding him, I felt something warm go past me. He went cold and the sun came up, as weird as that is. So I held him until Dezzie and Gabie showed up, probably about five minutes after he died. And they kissed him and then they stayed with him probably till one o'clock. Gerald's father's family was all up, none of mine were. So then Gerald's dad came in and wanted to hold Adrien and I think probably Gerald's brother and sister-in-law did as well.

Gerald - He died in our arms. I only wept when his heart quit beating.

Adrien died on March 25, 1995. He was nine years old.

As the Michauds are farmers closely connected to the land, they found the season of the year serves as a reminder of the dreams that were lost with Adrien. Of the children in the family, Adrien was the most attached to farm life. It was his parents' wish that he would take over the farm when he was able, and it was a hope he shared. Gerald told me, "He was going to be the farmer". All his father had to do was begin putting on his boots and, without an exchange of words, Adrien would enthusiastically follow him outside to help with any chore that needed tending.

Succession remains an important concept for many of those who farm. It is a traditional idea embedded with connections to the past and present and future, signifying preservation, continuation, and appreciation of what has been worked for, struggled for and valued within a family over time.

Imagine the role Adrien had made for himself, had been given...and would never come of age to fulfill.

***

*"When someone we love [is dying], we don't say good-bye just once. We say it over and over. And we don't just say goodbye, we live good-bye."*
*(Staudacher, 1994, p.155)*

## Building Memories

The use of ritual enables families to create unique memories that can be cherished and preserved years to come. Memories born of ritual may adopt special significance following the death of a child.

### Mealtime rituals

A common ritual surrounds activities at family mealtimes. Families often identify certain meals of the day, such as dinner, as the one time set apart for discussion of family interests, affairs, concerns, and plans (Fulghum, 1995; Imber-Black, 1988). Such occasions provide family members opportunities to communicate their feelings, to appreciate what they have, and to simply be together.

### Before we say good-bye

Food took on new importance for Adrien and his family. It helped them cope with the stress of Adrien's illness by creating positive memories, temporarily diverting their attention from the seriousness of their circumstances through humour.

The Make-a-Wish Foundation made it possible for the Michauds to go to Vancouver Island which fulfilled one of Adrien's dreams. The trip was filled with opportunities to watch the killer whales, hunt for crabs, and search for sea-shells. For the whole

family, it was a time to create memories. Many of those memories revolved around food.

Gerald - It was just the five of us and we ate lots of pizza and went for lots of drives.

Darlene - Adrien liked to watch T.V. in the hotel in Port Hardy. His favourite show was the Urban Peasant which just made me laugh. Because the guy made food, hey!

Gerald - Oh, yeah, as soon as the Urban Peasant was on it was just like, "MMMMMMMMMM!

Darlene - He really got an obsession with food there for eight months. Because of the steroids.

Gerald - Going grocery shopping, like we were saying was always a highlight of his day.

Darlene - We'd go to Costco and get his wheelchair and he would wheel himself around and look at the food and go to the samples. We thought that was so funny. (Laughs) We probably had ice cream with every meal.

Desirée - And remember the ravioli?

Darlene - Oh, yeah.

Gerald - And I'd go into town and he'd see a MacDonald's or he'd see a KFC or a Boston Pizza and he'd just "MMMMMMM!" and he'd start licking his lips and he was ready to go for dinner.

Darlene - Oh, he was funny!

Gerald - And he had just eaten.

Darlene - He gained thirty pounds.

Gerald - I mean, hell, I remember we always had to go through Fort Saskatchewan because we had to stop for those chicken nuggets at KFC.

Darlene - Or hot wings.

Gerald - Oh lordy! (Desirée laughs)

Inclusion, closeness and a bit of indulgence

The ritual element of inclusion may be particularly significant in a family where the membership is about to alter pending the death of a terminally ill child. The comfort of food and company can be in itself sustaining. Parents who are kept busy taking care of a dying child may be spending much of their time at the hospital. Consequently, family meals may be disrupted, but sharing a meal may become even more important in maintaining the family's sense of closeness and strength.

Being able to indulge in rarer, more exotic fare seemed to give Adrien the feeling that he was living life fully, and allowed his family to feel that they were doing as much as they could, even in small ways, to make each day for Adrien rewarding and memorable.

Desirée - If we wanted something, Adrien wanted some.

Darlene - When he got a little bit better, we would come down every weekend, We'd go shopping first, and he wanted to try crab legs and lobster and stuff like that, so we would buy it so he could try whatever he wanted. And we'd always get a little bit more because...

Gerald - You know, you couldn't drive, he was just finished eating and he'd be thinking about what we were going to have for supper now. You want to do everything you can to make them as happy as you can. And you spoil a little extra, but you can't help that.

Adjustment after loss

Resuming regular family meals following a child's death may also restore the family's sense of routine, thus providing normalcy and continuity. Those who ritualize mealtime or other designated times to talk about family concerns may find it useful to preserve this tradition so as to maintain a forum for discussion and reinforce unity.

But as the Michauds discovered, returning to routine without one's child can prove a disheartening challenge for a considerable length of time.

> Darlene - It was really weirdest part, you were asking things that changed...the first time we set the table for four, instead of five. People say, "How many children do you have?" How do you answer that? Do you say, "I have two and I had three", or "I just have two"? Those are questions I still don't like. After two years people figure you should get on with your life. They are thinking I should start living by then, maybe. But it's only been the last six months that we've really some normality and I am cooking again.
>
> Gerald - Yeah, exactly. Even the simple things become hard. I mentioned at the beginning of the interview, Darlene is an excellent cook. I mean, she bakes bread and she makes pies like nobody in this country makes. Chinese, or Mexican, or Italian. That disappeared for three years out of our family.
>
> Darlene - Yeah, two and a half years - I just quit.

Sharing and finding strength

Because mealtime rituals became so difficult for Darlene, they took new form. The evidence of Gerald's commitment to his wife and

family could be witnessed in his efforts to perform the roles normally assumed by Darlene as long as she needed him to.

> Gerald - We never suffered, but I had to pick up a lot. And I love cooking, and I like helping. But I never really did any of these things before. I mean, you may think I am a feminist pig or whatever but...
>
> Darlene - He didn't have time.
>
> Gerald - Darlene's mother and father raised her to believe that a woman took care of her husband...and I didn't mind that idea.
>
> Darlene - No man will.
>
> Gerald - I never did the dishes before, I never did the laundry, I never made the beds and all of sudden I am doing all these things. And I am not doing them because she is telling me I have to, I am doing them because I know I am helping. And, as I was saying earlier, the strength that you find, the things that you do. This is the kind of thing that my brothers and sisters can't believe. You know we go visit them and I'm the first one up clearing the table and doing the dishes. And they're all thinking, "What's the matter with you?" Well, you made changes, a lot of times it has been to the good.

While mealtime rituals may superficially seem quite simple, the Michauds' experience of them suggests their scope runs deeper.

***

*"If someone listens, or stretches out a hand, or whispers a kind word of encouragement, or attempts to understand a lonely person, extraordinary things begin to happen."*
*(Loretta Girzartis cited in Staudacher, 1994)*

## The Ritual of Telling the Story

The end of a sick child's suffering does not signal the end of their family's pain. When a child dies, the surviving family may find their lives fractured and torn. Part of their healing process involves the painstaking challenge of finding and gathering up the scattered fragments of hope. Indeed it may be only after being broken that wholeness is truly possible. But chaos generally precedes the restoration of order, and for many emerging from the depths of their situation seems a distant dream. In this context, grieving can be seen as an important ritual. An essential part of grieving the loss of a child is the ritual of telling the story of the child's life and death. It is with this recognition that this section is approached. My participants' experience of ritualistic storytelling in its facilitation of grieving will frame the discussion.

### Personal exploration

Meaning can be found through the grieving process and through the telling and retelling of the story. This exploration is profoundly personal as it challenges family members to carefully examine the development of their perceptions, reactions, and feelings about what has happened. Generated are inner reflections about relationships with self, family, friends, and others, questions about the very foundation of one's existing beliefs about fate, spirituality,

and God. It is a period of marked transition and change. While a family may long to "return to normal", life will never be quite the same, and neither will they. That is not to say that changes are for the worse, but the essence of who they are individually and of how they relate as a group will, in some ways, be forever altered as a result of their shared experience. With all these transformations, the relation to important people and interpretation of events shifts accordingly. Thus the story evolves.

My participants encountered impediments to telling the story of their child's life and death.

Choosing to keep the story private

There may be certain self-imposed restrictions on freely sharing a range of insights and emotions that may be thought as too private, too personal, too painful to mention.

The Michauds came to realize through their experience with Adrien's death how differently males and females tend to grieve, and how this, in turn, can impose strain upon significant relationships. They observed gender differences in both the parents and the children.

> Gerald - Something inside me died when we lost Adrien. Something's been taken...isn't there any more. But I don't want to relive that pain because I am the kind of person that thinks why put yourself through it? You are just hurting yourself.
>
> Darlene - I am the opposite.
>
> Gerald - Darlene always wanted me to talk about it. It took me a while to get her to understand that I don't

want to hurt, I don't like to hurt. I don't need to relive it. It is always there. It never goes away.

Darlene - But you dealt with it differently, I mean, I lived it. After his funeral I went through Adrien's stuff, I packed away his things by myself.

Gerald - But you were ready to do that and I wasn't and that was difficult for us. We both did things the other didn't like, but we understood the importance of give and take and I supported Darlene's choice as best I could. We have two different ways of grieving. I grieve by myself. I have to be honest, most of the time if I am out there doing something I will sit down and I will start thinking about him. I don't need to share my grief. It's there, it is always there, and I am in no hurry to get rid of it, if I can deal with it my own way on a daily basis. I go to work, I deal with it, in that I put it away for a while and then it comes back out. Until it starts to get sensitive...then that's it!

Darlene - Then they talk about work (laughs).

Gerald - When things get emotional I'll say, "Let's go for coffee, or talk about horses". So men kind of escape it. We'll never let it get too deep. In a sense we hide...well, we don't hide, we know it's there, but we don't want to share too much. That's what I figure because we don't want to...

Darlene - Don't want to hurt.

Gerald - Don't want to hurt anybody else.

Within the family, Gerald saw himself as protector and, in keeping with this role, was guarded in sharing his side of the story and the depth of his sadness with others. He wished to avoid experiencing and inflicting additional emotional pain. This was a

stance he assumed and maintained even outside his immediate family.

> Gerald - My brothers and I have always been very close and one particular sister, and they don't know, but I am scared to talk to them about my loss, our loss. To share my feelings with them.
>
> Darlene - We chose not to because they had been with us for the eight months and we knew they were hurting. We just chose not to hurt them.
>
> Gerald - It took me a long time to figure out why I don't like talking to my brothers about it and it is just that I am protecting them from my opinion. And it took me a while to figure out why.

However, Darlene preferred to share her story and found some catharsis, some comfort in being able to express her grief. Both parents observed behaviours in their son and daughter that were consistent with their own.

> Gerald - Darlene will go and reopen wounds easily. I can't. I won't.
>
> Darlene - For me its part of the healing.
>
> Gerald - Mothers are different from fathers and that's one thing, it took me a while to figure that men are definitely different and then I saw how Dezzie was and how Gabie was.
>
> Darlene - And Gabie does like Gerald. If I am talking about Adrien, Gabie will get up and walk away; he just doesn't want to talk about it. We have all handled it so differently, yet we are all hurting. But now I think we are all starting to live again, we are all starting to heal.

The need to tell the story

Another obstacle that often prevents family members from sharing their stories is that many people do not want to listen, don't know how to respond, and are made uncomfortable by the subject of death.

The Roaches commented on the fact that we, in this society, are not taught about grief, and we are left in a sorry position to offer our support to bereaved families and individuals who need it. Corry remarked that only one of her friends has stood by her since Lindsay's death, all of her other present friendships have been made since that time. So many people believe they lack the "right words" to say, and say nothing at all. They may even withdraw their friendship, as their own discomfort with the reality of death increases. Ultimately, as the Roaches pointed out, there are no magic phrases that eradicate grief. Simply offering families the chance to tell their story, expressing genuine sorrow for their loss, and remembering with them how special the child was, can be support enough.

> Brandi - I remember always crying much, much later especially after I started going to school where I was with the other kids. I guess around the house it was always O.K. to talk about her and what happened. And I didn't see any reason why it would be any different when I was at school.
>
> So if someone were to ask me about Lindsay's death, or if it would just come up in conversations when they were talking about their sisters, I would just tell them that I had a sister but she died. But that wasn't O.K. You didn't talk about that at school, and I didn't know that wasn't allowed. And I think that is part of

the reason that I was upset so much after I started going to school.

Corry - Once a woman came to the door and it was just awful. She threw herself at Brandi and said, "Oh, your sister, she's dancing in heaven with the angels".

Gene - And "It's wonderful, and there are toys and flowers!" And I was walking down the stairs and wanted to say, "Get the hell out of here!"

Brandi - I guess people were so scared that they didn't know how to react. In play-school my classmates told me that I was making it up because I wanted more attention. The only person that I could really talk to about it was my friend whose sister had died a year before that. And we are still friends now. But other than that mostly it was just "Heaven is a wonderful place and [we] should be happy!"

Gene - We always talked to your teachers. So that in class when they talked about families if Brandi said, "Well, I had a sister who died," the teacher wouldn't be shocked. Instead the teacher would say, "Oh, well then, you can tell us about her" or whatever. And we did that till you were darn near in Junior High School.

The need for support

Sensing the discomfort of others can put pressure on bereaved families to keep their story to themselves. Or they may deliberately choose to share their thoughts with only those few who are most familiar, and who appear supportive.

Ironically, the Roaches sometimes found themselves reversing roles with those made visibly uneasy with their story, and taking on the role of comforter. This sort of response left the family's own

need for comfort unsatisfied. And, most often, the story was left untold.

> Brandi - Talking about it with other people makes me feel awkward because it has always been so natural here at home, and if someone asks me about it or I just tell them, they say, "Oh, well, I didn't know that." And they just totally shut down and it is me who ends up feeling awkward, like I should say, "Oh, it's all right, you don't have to comfort me," or "It's all right, you don't have to feel uncomfortable." And like people don't know, you don't have to say anything, you just have to say "Oh!" if they are interested. People don't know how to react and it's me that ends up feeling more uncomfortable with it.
>
> Corry - Yeah, it is the bereaved person who becomes the one feeling embarrassed that they dared to bring it up somehow. I mean there really is something odd about that, you know. That the griever is the one who needs to support the one who blundered.
>
> Brandi - I think I've kind of developed a kind of tolerance for people who have never experienced something like this, but they say something totally insensitive or something really stupid and I'll just look at them and think, "Boy, you are lucky that it's not your family. You're lucky."
>
> Corry - I remember a little friend of Brandi's calling her a liar when she told her about Lindsay. When Brandi said, "My sister died," the child's response was, "This is a joke, right?"
>
> It sure would be nice if somehow other kids could say something caring to little kids that are hurting, you know?
>
> Even I had a girlfriend say to me, "Boy, are you ever lucky that she died!" And I said, "And you are lucky that you didn't say this a few years ago. Because you'd be sitting there with a fat lip right now." (Laughs) You know? Like what a thing to say!

Brandi - Or "At least she died when she was young so you didn't get to know her."

Corry - Yeah, or "It was God's will." Or all those good little things that people do to try to fix you when you are not broken.

Brandi - And you can't explain it to them so you just kind of roll your eyes and think, "some day you will know."

Corry - Some day, because we are all going to die some time.

For the Raoches, the pain of bereavement was, in itself, terribly isolating, without their being inhibited by superficial stock-phrases that were inappropriate according to the seriousness of the situation.

These forms of response, while perhaps stated with the best of intentions, are insensitive and risk antagonizing or alienating families who are grieving the death of a child. Because of these messages, grieving families may not feel that there is sufficient permission, understanding or acceptance to tell their stories.

The need for empathy

Even those who have lost someone close, perhaps a child, are not always supportive of what bereaved families might say about their own experience.

The Roaches found that for some other bereaved families there was a temptation to discount another person's pain perhaps for the reason that it is difficult to imagine that someone else's life has been devastated by the same kind of emotional trauma.

The Roaches identified an important point: comparisons of what has been lost cannot be objectively made, nor should they be. Each situation is unique and needs to be respected as such. When bereaved families support each other, the ritual of sharing their stories, among those who are in the best position to empathize, becomes manifest.

> Gene - A lady said to me once, "How can you tell me that the death of your child after you've only known her for 26 days is a significant or hurts as much as my husband when he died after 58 years of marriage." And at first I was stumped, but then I forget how I phrased it but I said, "You don't measure the quality or the intensity of the relationship by how much time has passed, and it's not a contest."
>
> Corry - Yeah, it's not a matter of seeing whose relationship is stronger or seeing whose pain is worse.
>
> Gene - And that is the trap you fall into, so I just try to neutralize it and say, "it's not a question of who's relationship was bigger or more important, it just is present and exists".
>
> Instead - without getting into the argument about who hurts more or how do you measure pain - I would probably say to them that we were as devastated as anyone could be without comparing their experience is to ours. And that we are living proof that you can come out stronger. I know that they are awfully hollow words for months, or the first few months you have.
>
> Corry - That's right. I recently was in Yellowknife and I met this fellow whose little two year old is dying of a tumour in the eye and what I said was, "I can't imagine what you must be going through, and I am a bereaved parent." And "If there is anything that I can do to somehow help you or support you just know that you can ask. I am not afraid of being in close quarters with that kind of thing."

The need for sympathy

A full understanding of the magnitude of the loss cannot be taught, and cannot be learned. Only the actual lived experience can give a person that level of appreciation.

Still, the Roaches benefited from the compassion and sympathy of a few people around them. Providing a sympathetic environment offers families who have lost a child to terminal illness the opportunity to share their experiences and feelings.

> Corry - I had a friend who called me after her daughter was born and said, "You know, I just wanted to apologize to you. I thought I had some idea of the kind of pain you were going through. I can't imagine losing this baby" And I just said, "Thanks for telling me."

The stories families tell are a product of each member's effort to seek, find, interpret, and create both meaning and purpose within the context of their experience. The emergence of meaning from story can then provide comfort. The ritual of telling the story of a child's life and death is an act that helps families preserve important memories of their experiences and maintain the connection between surviving family members and the deceased child. There are other rituals and elements of ritual that serve the same purpose, and are worthy of closer examination.

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*As long as we keep people in our memory, we have not lost them completely." (Feifel, 1958, p. 127)*

Preserving the Connection by Finding Meaning

From the interviews, it appeared that three aspects of ritual were of particular significance in the creation and maintenance of a

connection between the surviving family members and the dead child. Both families participated in rituals surrounding the burial and memorial of the child. Their involvement with ritual was strongly associated with their need to gain a sense of control over some aspect of what had occurred, and to feel that they could continue to honour the child. As well, members of both families engaged in dream work, which fulfilled their need for assurance that the child was all right, and that the child was, in some way, watching over them. And finally, the families sought comfort in the symbolic elements of ritual, satisfying the need for personal or spiritual renewal.

Burial Procedures

Burial procedures, generally performed by strangers, become meaningful rituals when enacted by the family of the deceased child. For the Roaches, burying baby Lindsay where and how they wished was no small gesture. It was the first of many steps on their journey towards healing.

> Gene - We wanted her buried in Trochu, which is Southeast of Red Deer, a small town, and my family has lived there for...
>
> Corry - Generations.
>
> Gene - It must be twelve or something. And so they know the family name and when we finally decided that's where we wanted to have her buried, I phoned the town office and identified myself. I said we wanted to bury our daughter's ashes at the foot of my grandmother's grave. I just wanted to know if we had to

get a permit and what we needed to do, and was there any kind of a charge? And she put me on hold for 30 seconds and came back and said, "Yeah, that's O.K." And that was all there was to it, there was no paperwork, but if it had been in the city we probably couldn't have done it. And it would have been 100 dollars and fill out three pages of forms and wait until you get a permit three weeks later and all that crap. I asked her, "So I can just go and dig a very small, shallow hole and put in the cremains?" and she said, "Yeah, that's O.K."

The alternative was to have a grave that was on the opposite side of the road, and she would be completely by herself over there.

Corry - And that wasn't an alternative.

Gene - So the only reason we got away with it was because in a small town, I mean, they didn't even charge us for the site even - although they could have.

With this rite of burial, the helplessness caused by watching one's child die may diminish. Participating in the ritual of burial also helped Gene regain feelings of competence and self-mastery.

Gene - I think it was important to be the one to bury Lindsay. I always said that we couldn't...how did I use to phrase it? It was the one thing that I could do for her. I couldn't fix things. I couldn't make her better, I couldn't take away her pain, I couldn't make her live, I couldn't stop the surgeries, I couldn't do anything. In that whole experience we were just like pawns. Even when you were pregnant it was just like, "Well, what's next?" And we'd just react, that's all we did was react. So it was the one thing that I could take charge of and do. Even though it was not a big deal, you know.

Corry - I thought it was a big deal.

And then Gene dug the grave with his dad. And there was just the three of us and a girlfriend with her baby and Gene's parents and the minister for the burial service. We had her buried at home. And then the

> minister did his thing. He read a poem I'd written. We addressed Brandi's concerns that the hole was pretty deep and wouldn't Lindsay be cold? We dealt with all those issues and we had Brandi sitting right there.

During the early stages of the grieving process, devising rituals that are truly unique in nature can alleviate some pressure experienced within the family by providing outlets for self-expression.

For the Michaud family, designing Adrien's gravestone was a particularly meaningful and creative ritual, which allowed them to focus their creative energies in a positive way that Adrien would have appreciated.

> Gerald - You asked if we did anything special for Adrien. That's it, we designed his tombstone. You see here, on this paper...I've got to keep this as my only copy, but Adrien's nickname was Critter and we named our farm Critter's Corral Farms. And he always wanted a farm, so you will see the farm, there's his quad, and that's his dog there...
>
> Darlene - That's Cody.

Placing personal touches on standard ritual ceremonies has the effect of making these events more memorable. The Michaud family challenged convention, replacing traditional church music with Adrien's favourite music, songs by the Beatles. While the emotional shock of Adrien's death left the family unable to absorb the event, their attention to making the burial and memorial rituals unique entrenched the day in memory.

Gerald - Adrien was buried with his motorcycle helmet. He did so much and he did so well. He was just a little guy yet he would start the kick-start of my trike at 200X, and my older brother was 45 years older but couldn't do it. Adrien had that much drive, eh.

It was the first time the Beatles were ever played in the Catholic Church in St. Paul because Adrien just loved the Beatles. I asked the priest because I had given Adrien a Beatles set for Christmas and he put it on there. And he played Beatles for the first hour, basically. We were in our own little world.

Darlene - We just went through the motions, we weren't really there.

Gerald - Just to show you, we could have gone in different vehicles and let somebody else drive but I am a very independent sucker. I had my own vehicle, my two kids and my wife in my truck and we went to the gravesite and we followed the hearse and there were other things we did that you think about later and they don't really make a lot of sense, you know. But that's the way it goes and then we pulled through it all the way on our own. We made the arrangements, and we had help of course, but we made all the decisions, we didn't rely on other people to decide things for us.

Darlene - We knew what we wanted. You just go through the motions. You are not really there; you just go through it.

Gerald - You know what is going on but you still can't, you are kind of in disbelief, it can't be real.

Ritual symbolism of place

While being able to dig Lindsay's grave, and design her headstone were meaningful rituals for the Roach family, the ritual of visiting the baby's gravesite held different meanings for the family members.

Gene - When you go back to the grave there isn't a connection.

Corry - She didn't live there.

Gene - It is like you touch, it is like you touch a stone and it's just still not real, it is just not real. It can't be, it is your daughter, and sister, it can't be my daughter, this still doesn't make any sense sometimes.

Corry - Yeah, she didn't live there, she lived in the hospital.

Gene - She didn't die there. Going to the grave still hurts. It doesn't upset me, but it hurts. But no, I don't feel connected, it just hurts, and I just go and I just shake my head and say, "Wow!" It was such an experience and it was hard to believe we went through it, hard to believe it can even happen, hard to believe people can go through that.

Corry - Hard to believe it is fifteen years now.

Gene - And it's so hard to believe it even happened. I mean, as I said, it touched us in 1983; I see my family name on that gravestone, just touch it. It just doesn't make any sense still sometimes. And it could have been fifteen or twenty years ago or it could have been last week.

Corry - For me going back has never had an impact really. I could never connect with it. I have tried, or wanted to but I couldn't, she's not there.

For Brandi there seems to be, or has been in the past, quite a strong connection for you there.

Brandi - Uh-hmm...I don't feel her presence there as much as I do in any other given place, but I guess just going there kind of brings everything back to the one place where it all ended. I don't remember being there and watching her being buried. It doesn't matter if I haven't been there in four years, I always get out of the car and I always know right where it is.

Corry - Well, you do, you never ever miss. It is kind of awkward where the grave is, but she never misses, she finds it faster than I can.

And it's a place where there is permission to feel no matter what you feel and no matter how long ago. It's O.K. when you are there. I think that is perhaps one of the things that I get from it is the permission to reminisce, to just think. To just be with essence of memories of her.

Still, there is something about going to the cemetery. I don't know what that is, it is rare for me to have an emotional time at the cemetery, and I don't know why that is.

And Gene, that is the first time I ever saw him really fall apart, was at the cemetery. And Brandi gets a lot of emotional release from going there, too.

Brandi - It gives me time.

Corry - It is like this is your release for you and her, it is your time together in the one place in the world where you have permission to totally express what you need to express what you've got inside. And I don't know how come I don't experience that.

Brandi - I think it's because if I ever want to - not talk to her - but just think about her I can. No matter where I am...and it is not like that for everybody.

Even within the same family, places will have different degrees of symbolic importance.

Desirée remembers more about sharing time with Adrien before he became sick and yet she feels most closely connected to him in hospitals. Gene also felt this way. For him, the Neonatal Intensive Care Unit at the Royal Alexander Hospital where Lindsay was born and died held more meaning.

Gene - It was just a maze of images in my mind. So many experiences and all the emotions were just kind of going

> everywhere all at once. And I didn't go back out of any desperation or anything, I just wanted to go back. I don't know, maybe to make it more real or to ensure it really happened or ensure she lived and died.

This range of sentiments was echoed by the Michaud family. Darlene alone found Adrien's grave a place she can feel connected to her youngest son, where she can gain strength when she is feeling vulnerable, and find answers when her thoughts are confused.

> Gerald - For me it doesn't mean a lot to go out to the cemetery. I go when I can. I drive by it probably three times or four times a month, I will stop by maybe once or twice a summer. But it doesn't mean nothing to me.

> Darlene - The children don't like to go out there. But I go out by myself a lot and I talk to him and I deal with a lot of stress or work through decisions I have to make. I will sit on his tombstone and I cry and I talk to him. For me that is sort of healing.

> Gerald - Well, it is exactly as I said, earlier. And Darlene said it too, she will go and reopen wounds easily. I can't, I won't. I don't really feel connected to Adrien at his grave.
>
> Actually, wherever I am, in my heart basically is where I feel the connection. I mean, I'll be driving down the road some days and I will stop and take a walk out in the fresh air and just clear my mind and get things over with and then get back to work. Or sometimes in my office at work all of a sudden I will look at that little sign he drew on my desk there that says, "Dad's desk. Don't use it." And I still have that on the wall. I am connected to things like that. But it doesn't have nothin' to do with the gravesite, because he's not there. I carry this (the paper with the design of Adrien's tombstone) is my briefcase, that's all I need.

Whether a specific place embodies a connectedness for members or not, simply taking aside some time to think of shared memories of a child can reinforce the connection.

For Gene, doing this not only reconnected him to Lindsay; it also altered his perception of the connection between past and present. At one moment, Lindsay's life and death might seem to her father an eternity ago, or conversely, almost in the here and now.

> Gene - Sometimes I think of her and just for an instant it becomes real because it was so long ago now and it's like did it really happen? I go down to the grave and I touch the stone 1983 and it could be 1883. And yet when we talk about it, it's all so fresh. Sometimes it's just for an instant during a busy day. For an instant it's real again.

Collecting mementos

Other rituals contributing to the memorial of a child also have the potential to heal the wounds of grief, as the family may feel empowered by their efforts to create a tribute demonstrating how precious and loved the deceased child had been.

Both the Roaches and Michauds collected mementos that were a testament to their child.

> Corry - I didn't want an urn. So I got a cedar jewelry box and gutted it and filled the inside with cotton batting and then put material over the top that was the same material from a maternity top I had made when I was pregnant with her. And then I put in little decals of little ducks and ice cream cones and stuff from my best friend. I wrote a couple poems and put them in where the mirrors used to be, a copper cross that Gene gave me when we first met, a stickpin with a rose on it, and some baby's breath from Gene's mother, and a birdie beaver stick pin from Gene because he's a forester. I also put in

> one of those brown Bozo bears from Brandi and then sprinkled some Chantilly powder - because that's what I always wore - all over everything and then sealed it. I was thinking the whole time I'm totally crazy for doing this. But it was amazing how healing that was after I got over feeling weird about it.

As a commemoration of Adrien's life, illness, and death, the Michauds collected mementos that had belonged to Adrien during his short lifetime.

> Darlene - When we took Adrien to the States for treatment we got this in Manhattan. He wanted to go to the Big Apple, so we got him a big apple. We got little things from New York and...I have his teddy bear. The year that Adrien was diagnosed he called me the last day of school, was it, Desirée? He had won a bike, so we still have the bike. And he won this little teddy bear and I still have that. He had been to a seminar with the doctors, when he went in for his next MRI and they had set down this big bag of teddy bears, and the teddy bear is on my bed. With three children you definitely get more money from Family Allowance, and so with the last cheque we received before Adrien died, I bought a little farmer. It is a little porcelain figurine, a little farmer boy, and that's my Adrien. I have a box of his stuff. Things like his report cards, and cards that people have written to tell me what they thought of him as a person.

Collecting treasures, creating traditions

Memorializing a child's life and death is not an act that necessarily need be confined solely to the days immediately following the child's passing. Meaning and healing can continue through new or repeated uses of ritual throughout one's lifetime.

Brandi still cherishes a keepsake she created the year Lindsay died.

Brandi - Well, after Lindsay died, Mom and Dad went to some kind of workshop and I stayed with my kindergarten teacher. She had a piece of pink flannel or felt. She gave me that and she took a black marker and she wrote Lindsay Ann on it for me and she drew two hearts. And then she gave me some lace and I sewed it by hand all around the edge of the blanket, and then I sewed red thread along the hearts and along her name. I was really small...only four years old and I still have that.

Corry - And that was up in your room right until you moved. It's neat to hear her say this because she says it is a blanket and we thought it was a pillow. (Laughs)

Gene - It's so small.

Corry - And she thought it was a blanket for Lindsay and it would have been, Lindsay was only this long, you know. Isn't that neat, so even right now there is a difference in perspective. It's so cool to hear you say that.

A physical manifestation of the lost child can be conducive to transcending grief. Families may want to collect some valued items that belonged to, or were intended for the child, for the purpose of creating a memory box.

After their baby's death, the Roaches were hurt because some of their friends would not give them gifts meant for Lindsay. This lack of recognition from others made the collection of little treasures for Lindsay's sake all the more meaningful for her family.

Gene - We do some traditions that came from Lindsay. Every year we put on a new teddy bear onto the Christmas tree for her. Brandi has a bear named Bozo and he's a really interesting looking bear. He lost his nose because she peed on him when she was very small and he had to stay in the drier for three hours and whip

around. We put one of those teddy bears in with Lindsay's ashes in the box. Then the first year we decided to put one of those bears on the tree, and every year after that we added a bear of some kind on the Christmas tree. We didn't uphold the birthday thing for very long. Buying gifts for her, having birthday cakes for her, it was more painful to do it than not to.

Redundant rituals

Both families acknowledged the latter part of this statement - in time some rituals will lose their purposefulness and their capacity to generate healing and meaning and may be abandoned, or replaced by new, more helpful rituals.

Brandi - At first I thought celebrating Lindsay's birthday was important because I didn't want anyone to forget her, just because she was dead. I still thought that it was important. I guess I felt that her soul was a year older every time her birthday came around. Just because her body wasn't aging it didn't mean that we should forget about the important day.

Corry - Now it goes by, the anniversary of her death, I have no problem in not acknowledging that. I mean, I am aware that she is not here every bloody day of my life and so I don't need to honour that day at all.

Brandi - I think everybody recognizes it, but we don't all make a big deal of it.

Gene - I think we all think about it and we all take a deep breath and go on.

Corry - Her birthday is still darn tough, you know. But there is no need to make a birthday cake. Sometimes I do my own private little thing, which has more to do with prayers and meditations and things like that because I am always aware of her, she is in my bones and in my

soul. I always say, "her life may have ended, but the relationship will never end".

Like the Roaches, the Michauds found that continuing to formally remember Adrien was more difficult at Christmas than taking some private time to think about him.

Gerald - The first Christmas without Adrien? It was very hard.

Darlene - We lit candles for him.

Gerald - Yeah, we included the family, like we had him as part of the Christmas celebration; the lighting of the candles symbolizes the ones that we lost and so on and so forth.

Darlene - There are four candles and they each symbolize something different. And then your Mom sang his favourite song.

We did that for the first two Christmases and the last Christmas - it was the third Christmas without him - we said, "No. No more." I mean, we miss him, but it just made it too hard. Sometimes it made it seem so much worse.

Gerald - It's the same thing. Sometimes it kind of puts doom and gloom on the Christmas spirit for the other children. But the thought is always there and that's what counts.

Dream work

Sometimes the connection reveals itself through a symbolic moment, a dream, the disembodied presence of the child that has died. Corry understood from some of her experiences that Lindsay

returned her mother's love and that, wherever Lindsay was, she was safe.

Corry - We do dream work. She comes to me in dreams all the time. Lindsay came to me a year after she died. I was really tired. I had just come home from work. Liz (Elizabeth Kübler-Ross) says when you leave yourself blank then you leave yourself open to the other side. I was just lying back on the bed and I was staring at the ceiling and all of a sudden this face with those eyes just shimmered. I could see those eyes and that widow's peak for a hairline, and I thought, "That's funny, doesn't that look familiar?" And it shimmered a little further. I remember thinking that it was the same nostril that she had the nasal cannula in for the ventilator. Inside my head I said, "Lindsay, is that you?" and she said, "Yes, mommy." and I reached my hand out to touch her and she said, "Don't touch me because otherwise I can't stay". So I put my hand down and she smiled at me. It was the most incredible feeling. Then I asked her how she was. She looked at me. She looked right through me and it was like she loved me. Every cell of me was exposed to her and was loved by her...I don't know how to explain that kind of love. It was totally incredible. And then I asked her if she could say something and she said "I can't mommy, I'm a baby." And then I reached out to touch her. I wanted just to grab her and she was gone. And I cried, but it was total joy. And Gene woke up and he normally would say, "Don't be ridiculous." But he said, "What are you doing?" and I said, "I've just had a talk with Lindsay. I just saw her. She was here." And he said, "Well, that's nice". And he turned over and went back to sleep, no arguments, nothing.

Brandi shared some of the dreams she had had and we did dream work with it which was really profoundly healing. Do you remember what Lindsay said to you that one time? About when you asked her about how close she was? Do you remember that? You said to her in a dream, "How close are you really, Lindsay?"

Brandi - Didn't she say something about how I could feel her breathing?

Corry - Yeah, she said, "If you would but hold still, really still, you could feel my breath on your cheek, that's how close I am." And Brandi was very young. For her to come up with those words - and it wasn't her language. It was just so incredible. I have never ever doubted that her sister is here to support her, to be with her, to love her and to give her whatever she needs. That somehow Lindsay is helping Brandi when she needs her. For me it's not an issue at all. We were saying to her, "You don't ever have to worry, she is O.K., she is right with you."

When a child has died, families may feel that the spirit of the child lives on and has assumed a guiding or protective role. For Brandi, sensing the presence of her little sister offered needed reassurance in times of stress or uncertainty.

Brandi - I remember Lindsay was really small and so I took a Kleenex box and I'd pretend she was sleeping in it and I'd put it beside my bed. I would talk to her sometimes, and when I started going to school I would imagine that she was walking with me to school. It didn't occur to me that she wasn't.

Even now when I think about it and I think about if she had lived, it seems so natural and so real that I have to remind myself that she isn't here physically at least anyway.

Whenever something happens that seems out of the ordinary I get this feeling like she's around. It happened on the first day of college when I was walking to school - and it was the same as the first day of kindergarten - I didn't know anybody and I was so afraid I wouldn't be able to find my classroom. And I remember walking and saying, "Please, just help me". Then I found it and I knew she was there.

It's comforting until it gets downplayed by someone else and they say, "Oh, isn't that cute!" and they think that it's something that a kid would do...but it's so real. It would hurt me even now if someone said that's a neat way of coping. But it's not.

While Gene was not as inclined to support the idea of visitation, he also admitted to having been comforted by his baby daughter's presence.

> Gene - We went on a marriage encounter weekend. A kind of marriage enrichment thing. It involves a lot of letter writing back and forth and then conversation. You do some things to get communication going. You're given certain tasks and I was sitting on the floor writing this letter. It was really, really difficult to write. I was having trouble writing it. The tears were streaming down my face. I looked over to my right I don't even know why, and she was sitting right there. About six feet away a little white bundle with dark hair and a little diaper with fat little chubby legs pulled up just like babies do. I didn't talk to her, and she didn't talk to me or anything, she was just there. It was just for an instant.

In the Michauds' case, dreams of Adrien also inspired comfort and reassurance. Their relationship with Adrien was not severed by death because the connection was preserved in their hearts.

> Darlene - Well, I can tell you what's happened since he's died. And you can think I am crazy, I really don't care to be honest with you, because it did happen. After he died, probably two days after the funeral, I woke up in the middle of the night to find all the lights on in my house, and I knew I had turned them all off before I went to bed. The next night I made sure to turn off all my lights, same time, two o'clock, in the morning all my lights are on. I went out there and I said, "Adrien, you are not being very funny!" I turned off the lights, and that was the last time it happened.
>
> I have dreamt of him. He came to see me one night in my dream 'cause I was really upset and he said, "Mom! What's wrong?" and I said, "Adrien, I miss you so much." He said, "Mom, I have to be where I am now. I'd rather be with you, but I can't be." And he gave me a hug and kiss and I felt it, I felt him put his arms around me. And

> that's when I sort of said good-bye to him and he was gone. But a lot of times when I am sleeping I feel somebody put their arm around me. We used to sleep like that, he used to put his arm around me and we'd sleep like that all the time, and I feel it once in a while.
>
> Once, in a dream, when we first moved here I opened a door and I said, "Adrien, where have you been?" He said, "It doesn't matter now, Mom, I am home." And I do feel he's here and to be honest with you I think he did move with us.
>
> It makes me feel good that he is still with us and I don't know if that is my subconscious or what, but a friend of mine told me, "It's almost like something envelops you when you walk in the place". I dream about him, oh, probably once a month and it is usually good and it is usually involves him coming down and saying "hi" or smiling or whatever. And they do make me feel good.

Darlene's reference to her eldest son, Gabriel, suggests how not receiving this kind of comfort can be an impediment to coping.

> Darlene - Gabie's never dreamed of Adrien, and Gabie sleeps in that room and says he's never seen him. But Gabie is still not dealing with it either. He went to this family get-together last weekend and he was really, really upset. And he said, "You know, I am looking around and my little brother isn't around" and he is still not dealing with it. He has a hard time with the [extended] family. You do too, Gerald. I did better with our last visit than I have a long time.

Like Brandi Roach, the Michaud children have also felt that the sibling they lost is now keeping them safe.

> Darlene - Another time, just after Adrien had died, we went for a quad ride. We had a little 50 quad and we quadded. Dezzie went over the hill, she should have went straight down but instead her quad went back onto the trail and she said, "Mom, I felt somebody push the wheels

> back!" And she should have gone straight down the ravine. Gabie had an accident on his quad. His cousin was driving, they hit a fence and the quad went over, and Gabie says he felt somebody push the quad off of him and onto its four legs. He broke his collar bone, but he said, "Mom, I felt something push."
>
> It's just weird things that happen, and either you believe them or you don't. But I do believe Adrien is with us and I believe he is looking after us.

The power of symbol

Families may develop a strong association between a symbolic item and their child. The symbolic element of ritual is often deceptively simple, yet also may carry the most affecting emotional impact. For the Roaches, roses have especially poignant meaning, reconnecting the family to their memories of Lindsay.

The rose

> Gene - Sunday evening at the marriage encounter weekend they have a big banquet. Throughout the weekend they have a vase with a rose sitting at the front where they talk to all the couples. It was a real rose, in the beginning it was a bud, and by the end of the weekend the bud has opened up into a rose. It's a symbol of what they hope will happen in the marriage. The rose is also a symbol of Lindsay's life and death. We have a rose on each side of her tombstone then her name and "The Rose" is printed underneath. And so whenever we see a rose, it hits us really hard. It seemed kind of interesting that this rose blossomed the whole two days. And then at the banquet a lady walked up to me and said, "I am supposed to give you this rose". And I said, "Who told you to?" and she replied, "Well, I don't know" and then she added, "I'm just supposed to give you this rose". And I was pushing her, "Why are you giving me

this?" and she wouldn't say why and she disappeared, and I'm just holding this...stunned.

Corry - And then at the banquet we got to talking a little bit, and we told her what the rose meant to us and her eyes filled up and she told us that she'd lost a son two years ago. And none of these people are bereaved parents so who knows, maybe her son told her to give Gene the rose. But he needed it. He really needed it.

As Corry suggested, the rose has become such an emotional symbol for Gene that it serves a need within him. The development of this need reveals the overwhelming power of symbolic ritual.

Gene - We attended an Elizabeth Kübler-Ross workshop about three or four months after Lindsay's death. They really strip away a lot of your façades and masks; they get down to some of the core issues. On Thursday night there was a party and there was a girl there from Edmonton whose boyfriend sent her a dozen roses for her birthday and she walked in with her roses. She wanted to give all the men one of these roses because only ten or twelve out of seventy people were men. And she wanted to acknowledge that men have trouble with their emotions and she handed each of us a rose. Of course the rose for me...I was pretty choked up. When everyone went back to what they were doing, this girl started picking the roses back up again. Symbolically she wanted to give each of us a rose, but she wanted to collect them all back again. And when she was collecting them I was in a state of panic because I couldn't give this back, I just couldn't. And I was sitting on the floor holding it thinking, "what am I going to do? What am I going to do?" Because I couldn't give it back. And she went to this guy on one side of me and he gave his back to her, and she skipped me and went to the guy on the other side of me and he gave his back to her, and she kept going. I was stunned. I was speechless. It still kind of boggles me.

Corry - And Liz gets so mad at him when he says, "I don't know about this divine intervention stuff."

Gene - Another strong association is when we hear the song 'The Rose.' I just fall apart. I heard it in the car once and I had to pull off the road. But it isn't a negative thing. It just really gets to me. And it's only when Bette Midler sings it, nobody else. I don't know why,

Corry - It has to be Bette Midler.

Gene - I just fall apart. It is a good fall apart; it's not all bad.

Cody

The chosen symbol is not necessarily a thing, but can be a person, such as another child, or an animal, such as a favourite pet. Adrien's immediate and extended family share the impression that the essence of Adrien's spirit lives on, not only in dreams but also in his beloved dog, Cody.

Adrien's strong attachment to Cody formed during the last year of his life and was transferred over to his surviving family when he died. The fusion of this relationship may have well been born out of the need to maintain connection.

Gerald - Nobody could say anything about Adrien and get away with it with Cody around. Cody come here, Dumb-Dumb! This here, this is Cody, "Come here, Baby!" Now this dog here, we asked Adrien what he wanted for Christmas, his last Christmas, and he wanted a Chocolate Labrador Retriever. So fate had it that we found one, Darlene and I, we both contacted the same man the same day.

In a way, she has replaced Adrien.

Darlene - She has got a lot of his characteristics, which is really bizarre. The kids, you don't hurt that dog, that is their sibling, basically.

Gerald - It is just a little bit of his spirit living on. So these are the kind of things that will happen, hey.

Darlene - Our friend Gail did the same thing. Her son died of cancer a month after Adrien and somebody had given her son a dog and she said, "It is true, it becomes your child." It becomes like your child, and I am sure that when something happens to Cody we are going to die inside, I just know it.

Gerald - It's funny that it would come to that, but it is reality.

Darlene - I should say, I never thought I would be a person who would bring a dog anywhere with me, but she rides in the cab with everybody and it's really kind of strange.

Gerald - It's like three kids in the back seat of a truck.

## Rituals of Renewal

Families may reach a certain point in the healing process at which they feel able to begin new rituals, ones that are perhaps inspired by the loss of their child, yet that do not revolve around the child. These are rituals of renewal, signs that the family, while still connected to the child, have found a way to move on. Some families recognize these rituals as a part of the child's legacy: something positive and powerful stemming from their tragic loss.

Creating new traditions

The Roaches discovered that a newly established ritual designed to help others would also prove healing for them.

> Gene - It must have been the second or third Christmas after Lindsay died, we just decided we had to do something to turn Christmas around. The first Christmas was a disaster and the second one was not much better, so we talked about how we had to do something to turn it around.
>
> And I don't know whose idea it was first, but we started by talking about all the places where they needed Santa Claus most. And we thought of hospitals and we thought we could go into them because we weren't scared of Neonatal Intensive Care Units or tubes and it wouldn't bother us.
>
> So this kindergarten teacher helped us make a costume, a Santa Claus suit, and she had a crushed red velour robe, and made a hat, put trim on it, and made a long robe. I even have little tiny glasses, little tiny square glasses that a friend found at a garage sale. And I took them into an eye place and said, "Here is my prescription, can you grind lenses to fit these?" And they are really tiny, about this big, really small. And the guy looked at me kind of strange and he said, "Yeah, I guess I can do that but that is an awful small frame." But he said, "O.K., I'll get the form and so he starts writing and I said, "Claus." And he started to write and then he laughed, he knew what it was for. He only charged me for the glass, he never charged me for all his time. Every year I add a bit more to the costume.
>
> So I think that whole thing has been really healing for me anyway, to do all that. I go to few schools and a couple of hospitals and I go around to the houses here at the beach. I think that is why Christmas is tougher. It's not exactly difficult for me, but it is more emotional because I know the impact that my being Santa Claus has had on David and Brandi. I'll come in and even though they know it's Dad they give me a choking hug. So I know it has made a difference to them, and it has made a difference for me too.

Corry - It's great. We always try to do it on Christmas Eve and then we open the gifts right after that. So it's kind of a highlight of what the beginning of Christmas holidays is for us since Lindsay's death.

Moving on

Starting over is an essential part of the ritual of renewal.

For the Michauds, part of moving on meant moving out. The family felt that finding a new home where the memories of Adrien would not be as haunting was necessary in order for healing to occur, but they soon experienced that rituals involving new beginnings are not always easy.

Darlene - We decided to move because our other house was full of memories. Memories you can bring with you, but it was just too hard staying there. Now that we have moved to the farm we have new memories as a family of four, not a family of five. My memories are still with me. But I remember moving. Moving was really tough.
Gerald - Leaving the house was tough. Darlene knows that Adrien moved with us, she feels his presence with us. I don't get those feelings, and it's fine. Although I do dream about him. I see him in my dreams, and he will talk to me in my dreams once in a while.

***

*The cry, "God, why me?" echoes in the empty stillness of my soul. And slowly, so slowly, I realize that an explanation is not what I want. I want to be comforted, consoled. I want God and the people in my life to know that I hurt. I want to be loved, held. I want to fill the emptiness my loss has left within me.*
*(Schwartzentruber, 1986, p. 22)*

A Final Tribute: New Beginnings

Without the use of ritual, the process of finding and creating order and meaning after the experience of losing a child may be

intermittently interrupted. The healing process is slow and gradual and is unlikely to progress in a linear fashion, but instead may begin, falter, and regress, before continuing on. Progressing through grief work and searching for acceptance can reduce a family to their lowest point before genuine comfort is found. As a means of alleviating their despair, the act of creating a tribute to honour and preserve the memory of the life and death of a child may be one of the most meaningful and healing rituals bereaved families can perform. Tributes have the ritualistic quality of varying in degree of structure, and for this reason take a wide range of forms as the stories of the Michauds and Roaches demonstrate.

This section's focus on creating a tribute is based upon the challenge taken up by both families to question, find, and preserve the meaning of their child's life and death. I chose this perspective as a way of supporting what I believed was the emerging theme of the interviews, that finding a way to heal and continuing on are the utmost tributes a family can give the child who has died.

Answering the unanswerable

Initially, before the family develop their tribute to the child, they will likely undergo a lengthy period of introspective questioning. For many families who share in the experience of losing a terminally ill child, a lifetime of perceptions and values will be heavily tested, no matter how firmly entrenched they had previously been.

Many people, whether they identify themselves as religious or not, feel in times of trouble that there is some greater force acting

against them. Parents whose lives are guided by spiritual principles may suddenly find themselves seriously questioning the existence or goodness of a power, which "allows" or "causes" the death of their precious child. Perhaps, on some level, the testing of spiritual relationships and beliefs can be compared to the trials experienced in other significant relationships. Both can become strained as the initial anguish of loss manifests itself as inward guilt and its companion of outward blame.

Why our child?

The Michauds' struggled with the injustice and seeming betrayal of faith by their tragic loss. They felt isolated and alone in their grief. The pain of feeling forsaken was strongly voiced by Adrien's mother and father.

> Gerald - We always asked the question "why". Why Adrien? Why the baby? Why the little fellow? Why couldn't it be me?
>
> Darlene - You always think, "Why did they pick us?" I mean, what makes us so damned special?!
>
> Gerald - And then also, why anyone else? It is just like a game of chance, you got to believe in fate and destiny. There's all kinds of things that come into play. I mean, religion, a good example. Since Adrian's death I haven't been back to church. Why?
>
> Darlene - Gabie still won't. Gabie is still very angry with God. You get very angry with God.
>
> Gerald - That's what happened. I am upset, I was mad with God and I talked to Him. It is not that I don't believe, but I just...

Darlene - Question.

Gerald - It happened to me, it happened to my family, it was my son. And I prayed and I prayed and I prayed...We all prayed.

Darlene - When you watch other people and their miracles and they prayed and their child's tumour went away, it kind of makes you angry. Still it'll probably always make me angry because I am thinking, "Well, everybody prayed for him". We had prayers all over the world and he still died.

Again and again parents struggle with the question "why our child?" Gerald talked about how hard it is for him, seeing boys who are the same age Adrien would be now had he lived. He said, "You feel resentment, but we always follow those feelings through."

Queries such as Why are the good made to suffer?, and Do good and bad things happen to us because someone (God) or some force (fate) so chooses? have a long history of serving as themes for philosophical discourse, religious thought, literary and dramatic conflict. How families who have experienced the death of a terminally ill child resolve these dilemmas will shape their beliefs and influence the kind of tribute they make to the deceased child. For instance, if they believe that there is a higher power, such as God, that causes people to face hardship and tragedy, they might struggle with what kind of God He is, how to continue believing in His goodness, and how to resolve their conflicting feelings of anger, hurt, betrayal, and faith. How do they reconcile within themselves such hollow condolences as "it must have been God's will" or "God must have wanted your child with Him"? Under these circumstances the

spiritual connection can become vulnerable. A deep schism may develop under this kind of duress, and images of a fair and loving God may be displaced by those of an unjust and punitive God. Some families may find their relationship with a higher power to be the only constant through troubled times while other families may find the split is total. Yet some may have their loyalties shaken but intact. Still others may become closer than ever, and a few who never were inclined to regard themselves as spiritual, may find that they become so. It can take a long time before spiritual convictions offer solace. These thoughts, emotions, and questions can be viewed as part of the grieving ritual.

Schwartzentruber (1986) suggests that the question "why?" is not a genuine question and does not have a comforting answer, rather it is the soul's expression of anguish and despair that begs for sympathy and understanding. Arriving at the ultimate conclusion that a child's death may be no design of fate, no product of good or ill will, but something tragic that happens beyond the control of anyone or anything may serve to comfort some, but only perplex others. If we consider the evolution of meaning to be the foundation upon which many tributes are based, then the manner in which these spiritual issues are resolved becomes central to the family's tribute to the child.

After Lindsay's death, Gene and Corry Roach underwent divergent experiences in their attempts to resolve their internal struggle with their altered relationship with God.

Corry - My spiritual nature has been cemented by Lindsay's death. When Lindsay was born I always thought I believed in God - I thought I had been challenged enough as a nurse when people were dying and being born in front of me all the time. I wasn't raised in a church, so I didn't have a lot of guidance and structure, but I did a lot of my searching on my own. When we lost Lindsay, I called God every filthy name in the book and challenged him to crucify me. I tried to make a deal, to do whatever it took. And what it came down to was I wanted him to hate me as much as I hated myself in the hopes that I would heap more wrath upon myself so somehow the outward pain would equal the inner pain. I was in God's face "Listen, asshole! Get out of my way! You're not going to let me go through all of this and give me a baby and then take her away. Is this your idea of some sick joke, making a child suffer like this?" And then years later what I learned was that God loved me more and could say He loved me one more time than I could say, "I hate me and I hate You". It's about maturing into a spiritual relationship where you learn to understand that there is meaning. You can find meaning in these things, but it does take time and it does take healing and you have to work through that stuff because otherwise it stays as this terrible pain. It doesn't heal on its own. And as they say, "people can get better, or they can get bitter". And what came out of it, after all the kicking and screaming and everything else that we go through when we are grieving, was that the love was there as solid as could be. And I don't ever have to question now that I am loved because it is always there. And I don't ever question whether God is any more. And I can use the word God, or Creator, or whatever, something greater than you and I. I think it has made me a more tolerant person perhaps.

But I think one's own spiritual belief is something that is very private. Your belief, Gene, I think really took a beating and never really did recover.

Gene - What little I had probably did take an awful beating. I don't think I consciously rejected it all, it just didn't have a whole bunch of meaning. I don't think it

had a whole lot before, but what little there just kind of slowly evaporated.

Seeking practical answers

Because men aspire to being problem solvers, their search for personal meaning may take a more instrumental direction. Gene sought information to further his understanding and acceptance of the loss of his baby daughter. His attempts did not fail, but rather brought him to a different point than he hoped. In time he came to the conclusion that there is no answer that satisfies the question "why?". Gene's understanding would serve as part of his tribute to Lindsay.

> Gene - Losing Lindsay was incredible turmoil. I couldn't fathom it or understand it, and I tried desperately to understand it. How did this happen? Why did this happen? Why us? What did we do, or not do? I knew I couldn't change anything or fix anything. I just wanted to understand it. I wanted to know what happened. It didn't make sense, and the more I tried to understand it, the more frustrated I became. It was a rude awakening, all the things that science can do yet there are still so many things that science can't do, and can't answer and can't explain. There were no answers. There's just nothing to understand.
>
> I read every book I could find. I talked to people. Corry did it all internally. I did it all externally. I don't actually think I found a whole lot of wisdom from the books. I got most of my answers, whatever answers there were out of cartoons. Like a Ziggy cartoon was a real awakening for me. Ziggy was shaking his fist up at the sky saying, "Why?! Why?! Why?!" and the next picture was this voice coming down to Ziggy saying, "Why not?" And it was a real revelation to me...I mean, why not my family? My family is no more special than a family in Africa or India or across town. I think all the reading and the talking I did just let me spin my wheels enough

> to generate a little wisdom, and enough time passed until I found a comfortable spot.

Facing challenges in relationships

Trying to understand why things have unfolded contrary to the accepted norm entails personal discovery and rediscovery. Existing relationships can also be subject to judgement. In particular, responses to loss, both inside and outside the immediate family, can test the resilience of relationships. Expectations about people's loyalties and strength can be completely reversed when faced with a traumatic loss of the kind suffered by the Roaches and the Michauds.

> Darlene - You learn a lot about people. You learn a lot about who your friends are. You find out a lot of people can't deal with a crisis like this, and a lot of people you felt were strong, aren't. And then you find out that you are stronger than you ever imagined. But that's O.K. I know a lot of people still ask me how we did it, and to be honest with you, I don't really know.

Mending unravelling relationships, rather than abandoning them, presents a formidable task for bereaved families. It is, nonetheless, important that when they are again able, families should surround themselves with a few friends who can offer their support, compassion, and comfort. A friend who has undergone a similar loss may well prove the most empathetic, however death should not be the common bond for all close relationships. I believe that cultivating strong healthy friendships can herald the return to living which serves as a profound tribute to the child lost by the family.

Re-examining personal perspectives of death and dying

After the death of a child, the prospect of death is not necessarily seen as more threatening than it was previously, nor need it constantly preoccupy a surviving family member's thoughts. However, the reality of loss does become more natural to adults and children alike after the death of a child in the family. Darlene Michaud articulated her fears about losing her husband.

> Darlene - I don't know, I think my biggest fear now is if something happened to Gerald. And you do live differently, because you are always scared 'cause they say, "God only gives you what you can handle." Well, this was a biggy, so what's next? You don't want to think that way, but in the back of your mind you are thinking, that's next, and that would be the worst one for me, is to lose him. I don't want to lose him and I am hoping we die together one day so we don't have to deal with it. But that's my biggest fear now, is to lose him.

Finding and creating meaning

While many people feel infallible in their youth, children who survive the death of a brother or sister find that issues of mortality become more pressing. For them death becomes very real. Brandi, who lost her baby sister early in life, does not perceive death as a taboo subject avoided by most people in our culture.

> Brandi - I think what our family went through has given us a better attitude about death. And it is not something that we don't talk about or something that is scary. If I ever had a family I wouldn't want death to be something that was in the shadows and kept quiet - it is just as natural as being born. As natural as life.

Although Desirée's feelings about death and dying were somewhat ambivalent, both she and Brandi developed attitudes towards death that seemed remarkably wise and precocious for their respective ages. The girls' acceptance of death as something natural reveals a tremendous inner strength, and this strength stands as a tribute made to the sibling they lost.

> Desirée - Death is definitely real now. Before I never really worried about it because it didn't happen, or I didn't think it happened. But now that I have seen it does happen, it kind of scares me more, yet it is kind of comforting because you know that when you do leave you had the best you could possibly have.

While some families may believe that there is some reason for what their child and family has suffered, others see no purpose, yet may still find meaning in their loss. The former statement was true for the Michauds, while the latter had more resonance for the Roaches. Finding or creating meaning from loss not only facilitates coping; it provides a testament to the meaningfulness of the child's very existence.

> Darlene - There is a reason why and why is something you have to accept. You learn acceptance. Acceptance is essential because you can't change things.

> Gene - I don't think I see it as making sense or as having a distinct purpose, but I guess there is a part of me that believes that the world unfolds as it is supposed to, and that is just the way that it had to be.
>
> But some of the things that I do and Corry's business wouldn't have happened if Lindsay had lived - she probably wouldn't be doing what she is doing.

Corry - That's true. My whole professional practice is because of my daughter. I would never have dared to make some of the changes in my life, face some of my demons, if it hadn't been for her. I know that sounds like I'm placing her on a pedestal, but I am not afraid of anything any more. If I look at how many people in my practice I've helped and so much of it is thanks to who I've become as a result of what I've done after Lindsay's life and death.

And those people don't even know its because of one little kid who got the ball rolling. They don't have to know, but what's neat is I know. And I feel as if Lindsay is patting me on the head and saying, "Good work, mom! Let's do something positive with this".

Gene - And a lot of the qualities that Brandi talked about, maybe they wouldn't be as strong in us. I do "Coping with Christmas" presentations every year in Stony Plain and we get 50 people. And I wouldn't do those if she had lived. We certainly never would have done Santa Claus, never in a hundred years.

Brandi - And we wouldn't have David.

The Roaches found ways to reframe their experience of loss into something positive for both the benefit of others and themselves. Their adoption of David, who has Fetal Alcohol Effects[1], and their contributions to non-profit organizations have all come to represent a tribute made in Lindsay's memory.

Coming to a point of acceptance takes healing, and healing takes time. By examining and enriching their relationships, helping others, challenging their philosophies and growing both individually

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[1] Children with FAE tend to have fewer and less severe birth defects than do those with Fetal Alcohol Syndrome, yet will often suffer similar challenges such as learning difficulties, hyperactivity, and disruptive behaviour. These problems may exert significant influence upon family, health, education, and socialization (Appelbaum, 1995).

and as a family, the Roaches and Michauds have honoured the memories of the children in a personally meaningful way. In finding or creating meaning from the experience of losing a child, a rewarding tribute was given to Lindsay and Adrien by their families.

Growing from the experience of loss

Both the Michauds and the Roaches expressed the belief that they have grown as a result of their experience with loss. They commented on the shift in their personal goals and values about things that have come to matter to them. The parents in particular had been made aware by the loss of a child of new perceptions about time. Members of both families felt the need to live life day by day and preferred to make only short term plans. Pain often causes us to withdraw into ourselves, but the self-awareness that comes from the search for meaning can lend itself to greater respect for other people. Towards others the families are now more compassionate and sensitive; towards each other they are more protective and caring. Despite their differences in coping styles, family members voiced the opinion that their marital, parental, and familial relationships have become closer and stronger through the trials of grieving the death of the children. Gerald reflected upon the origins of that kind of strength.

> Gerald - Together we found our strength. The source of that strength was love.

Corry and Brandi Roach talked about the ways in which they had grown as a result of coping with Lindsay's death. Corry's statements reflect resilience, wisdom and peace, her daughter's confirm the idea that the experience of loss of a child can signify the preservation and strengthening of the connection rather than its end.

> Corry - I honestly can say that I really do not feel bitter. I really don't. Joseph Campbell talks about how you follow your bliss. How you can look back on your life and notice all the places in your life where there has been particular hardship, and then you can put all those places together and connect it with who you are and where you are today. That's when you can truly say, "I am following my bliss." And it does become a bliss. For me there is a lot of peace in it now. I was born. They often say that when a child dies the mother is born. I know that if Lindsay hadn't died I wouldn't have ever gotten free of the horrific family that I grew up in. And my knowing what the love experience is, is because of what happened with her. And understanding that just because something goes bad doesn't mean it has to get ugly. I think I became a much better parent and certainly a much better human being. And I don't mean to sound hokey, 'cause it kind of sounds hokey, but it is really true that with her life and death I feel like I was born again. The true me was allowed to come out.
>
> Brandi - I think that because of Lindsay's death I am a better and a deeper person, and I think that if she hadn't died I would have a pretty limited perspective on the world. I just feel like I have so many more connections with her now and I feel like I am bigger inside because I think she is more a part of me than anyone who is alive would be. I think it has made all of us stronger.

One of the most touching tributes Corry made to Lindsay was to make and publish a collection of personal poems and expository

prose detailing the depths of her pain, sadness, and love. In referring to the purpose of writing her book, she articulated the meaningfulness and sacredness that can be derived from the ritual of creating a tribute to one's child.

> Corry - I didn't want anyone to hurt as much as I did. And I just wanted to do something that would make it so that she had not lived and suffered for naught. That somehow it made a difference that she lived at all. You can't go through something like this...you can't have this lifetime and just have it forgotten.

It is my hope that the families' words recorded in this thesis will serve as a tribute to Adrien and Lindsay as well.

# CHAPTER V

## Discussion

The terminal illness and death of a child are among the most devastating experiences a family can suffer. The loss of a child represents lifelong grief encompassing unfulfilled dreams, hopes, and expectations. Yet some people will find ways to cope with their pain, find meaning in their loss, and even renew their strength and commitment as a family.

In this thesis, I examined how the symbolic, sacred, creative, and healing elements of ritual enhance coping and meaning as families grieve the loss of a child. Ritual was recognized as a relatively adaptable yet meaningful component of a family's coping repertoire whose benefits can be easily accessed and appreciated by such families.

My research further demonstrated the manner in which coping progresses, meaning evolves, and ritual transforms over time. Rituals of diverse structures and types were assessed in relation to their ability to help foster meaning and promote coping within two participating families.

The healing family rituals that were drawn from my participants' stories included the rituals of building memories with the child, burial and memorial, relating the story of the child's life and death, preserving the connection to the child by finding meaning in loss, and creating a tribute to honour the child by finding new purpose and pleasure in life.

It is worth noting that family members did not always explicitly articulate what was symbolic, sacred, or meaningful about

their coping behaviours. Nevertheless, these elements clearly emerged from their stories about the events, activities, places, things, and private moments and thoughts, that have become meaningful to them. The ritualistic elements of symbol and ceremony can render words inadequate or unnecessary. And meaning may be understood at a deeper level through lived experience rather than as an expressed concept (R.F. Jevne, personal communication, March 9, 1999). Stories incorporating these elements of ritual revealed a range of meanings, perceptions, and definitions. Individual interpretation of meaning often superseded those of the family as a whole. The basis of this distinction was caused by personal and gender differences, unique coping and grieving techniques, as well as differences in the members' relationship with the deceased child.

The evolution of ritual over time

The four most prominent themes of my participants' stories revealed an evolution in coping and meaning as part of the grief process. While the data suggested that celebrating life and creating memories before the child died, burial, mourning, and divestment are among the more structured and shared rituals, the revival rituals of renewal and creating a tribute in honour of the child's memory were found to be less structured and more private. From this evolution of the families' experiences, I gathered that rituals performed early in the grieving process facilitate the progression of coping, whereas those that are performed later are essential to the development of meaning. The rituals of telling the story of the child's life and death and preserving the connection through finding

meaning appeared to enhance coping and meaning throughout. The stories themselves reflected these transitions.

The significance of ritual as a resource

Consistent with findings of previous studies, family ritual was found to be a resource that can facilitate the family's efforts to heal and find meaning in their experience (Hill, 1958; Koop & Keating, 1990; McCubbin, 1993). Also in keeping with earlier studies, this research confirmed that because ritual is flexible, it is able to meet a host of needs (McCubbin, et al., 1988), whether they be physical, intellectual, emotional, or spiritual. Among the specific needs that contributed to coping were the needs for control, continuity, diversion of attention, emotional expression and release. Those needs that enhanced meaning included the needs for understanding, acceptance, inclusion, change and healing. In many meaningful ways, rituals help create and preserve memories, and in this way maintain the connection between the deceased child and her family.

The nature of the grieving process

In recent years some researchers in the field have acknowledged grief as a life-long process (Benstein, 1997; Rubin, 1993). Yet the general public still appears to follow and believe earlier claims that grieving in otherwise emotionally healthy individuals takes two years and is then complete (Lindstrom, 1995). The commonly held misconceptions that grief is short-lived and progresses in a linear fashion were discredited by the stories of my participants. Both families made it emphatically clear that no matter

how much time passes, there are days when sorrow clouds every other feeling and tears fall. Bereaved families may benefit from the understanding that grief generally progresses in interrupted spurts. Moreover, they may be reassured that re-experiencing emotions they believed were already worked through is well within the realm of normality.

The significance of gender differences in grieving

This study upheld contemporary research findings relating to gender differences in grieving (Schwab, 1996;1990; Stroebe, 1998). It was particularly apparent in the Michaud family that the less structured and private rituals were preferred by the father and son, whereas the more structured and shared rituals were preferred by the mother and daughter.

The progression of grieving

Interestingly, I observed a similar distinction in relation to the stage of grief the family had reached. While early stories of coping with the terminal illness and death were often focused upon more structured rituals involving the whole family, later stories emphasized the resumption or commencement of less structured and more personal rituals. I felt that this tendency reflects the power of ritual to initially help families to heal and find meaning.

I also noticed that family celebrations, family traditions, and patterned family interactions generally tend to be of a more structured and shared nature during initial grief, but become more private and less structured over time. During a child's fight for life,

or in the period immediately following his death, families who do not engage in rituals or who chose the more private, less structured forms may encounter more disadvantages in coping. This problem may be attributed to the fact that without ritual many of the family's essential needs may not be adequately met. In later stages it may be that families who are experiencing serious trouble advancing through grief would also be found to be continuing the practice of more structured rituals. In so doing, these families might create something of a shrine rather than a tribute to their child. Families facing this dilemma may not be finding resolution because they are resisting the need to let go. These families can be helped to see that through ritual a close connection can be maintained while acceptance of the loss is achieved. Other families struggling with grieving may include those who were not encouraged or enabled, in earlier stages, to perform rituals. This information may be of particular use to those in the helping professions who assess how bereaved families are coping with their loss. Inquiry into a family's recent use of ritual may reveal obstacles in their progression of grief work. Experts can then provide the family with information about the healing potential of ritual and suggest examples of rituals of a structure that is more appropriate to the family's particular circumstances.

## Unanticipated Findings

### Reconsidering the definition of ritual

In my examination of this topic, I chose to consider family ritual in a broad manner. From most to least structured, I recognized ritual as including the following types: family celebrations, family

traditions, and patterned family interactions (Wolin & Bennett in Imber-Black, 1988, p.279-280). My investigation led me to the conclusion that each of these types of ritual can have a significant role in enhancing coping and meaning in families grieving the loss of a child. To some degree this idea contradicts those proposed by Wolin, Bennett, & Jacobs (1988), who dilineated three distinct levels of ritualization. According to their research, a "low" level of ritualization possesses more functional than symbolic meaning, and is characterized by flexibility or uncertainty in the participation, roles, and forms attendant to a family's ritual performance, by the ritual's lack of meaning or priority in the family, and by the vulnerability of the ritual to change as precipitated by internal and external influences. By contrast, a "moderate" level of ritualization maintains the flexible character of "low" ritualization, but the family places higher priority upon the meaningfulness of their ritual performance. "High" levels of ritualization are comparably more stable, predictable, and meaningful. High ritualization allows less flexibility in terms of participation, roles and forms and therefore has significantly more structured qualities. The authors agree that this third level includes the most purposeful, symbolic and meaningful of rituals. Yet my findings suggest that less structured rituals may be extremely symbolic in spite of their being flexible and having fewer concrete behaviours and symbols attached to them. In fact, I would argue that it may be the very internal nature of certain unstructured rituals that make them as meaningful and healing as they can be. It is perhaps easier to identify and explain the healing and meaningful potential of structured rituals because the behaviours,

places, events, and symbols are observable and, for that reason, can be more readily identified. I would further question whether "low" levels of ritualization are actually rituals at all. Sacred, soulful, and symbolic personal meaning are, I believe, what distinguish ritual from ordinary behaviour. I achieved this understanding of the scope of ritual through my efforts to explore the role of creating a tribute in enhancing coping and meaning.

From the contributions of my participants, I understood tributes to be personal and purposeful efforts towards growth and self-discovery based upon found and created meanings. This profoundly personal exploration for meaning and understanding is fraught with turmoil but may, in time, inspire peace and acceptance within. And this outcome may only be made possible through the most painful challenges which force family members to question their relationships with a higher power, the self, and close others.

In my original considerations of my topic, I assumed that ritualistic behaviours would be more structured than what some of the data revealed. As a result, I struggled for a while with how the act of creating a tribute in commemoration of a child's life and death should be represented. In comparison to other rituals explored in my analysis, honouring a child's memory through tribute is experienced as a far more internal process than I anticipated. Even among other rituals of renewal this observation appeared to be true. The search for meaning that serves as the foundation to this family ritual was unpredicted. And although I sought supporting evidence for my ideas about the meaningfulness of tributes, I discovered that the concept had not previously attracted the attention of researchers.

It has been argued that ours is no longer a ritualistic society. The increased influence of secularism, humanism, and science compared to the declining influence of religion have served as support of this criticism (DeSpelder & Strickland, 1994). Also contributing to this belief is the fact that where traditions such as burial formerly were carried out by families, they now generally fall to professionals. As a result, many people fail to see that ritual plays a significant role in their lives. Understanding ritual in a broader sense however, allows us to develop a greater appreciation for its necessity and benefit.

The role of the ritual of renewal in the enhancement of coping

While all forms of ritual appeared to contribute significantly to the development of meaning, the ritual of renewal appeared to be dominant in the enhancement of coping. The act of creating tributes to Lindsay and Adrien was made possible by members re-committing themselves to the family or marriage, by helping others, and by challenging personal beliefs and personal demons. This trilogy became manifest as the most meaningful way to honour the child's memory. Revival rituals emerged as the most important rituals in healing from loss. These rituals empowered families to move forward.

Re-addressing the application of theory

Having completed this study, I am now in a position to offer some definitional and conceptual clarification of the two theories that guided my ideas about coping and meaning.

I approached my research as if a unified conceptual framework were available, incorporating elements of both Family Stress and Symbolic Interactionism because I felt that they complemented one another. And yet even when integrated, my original criticism of these two theories remains. The focus upon behaviour and cognition, by Family Stress and Symbolic Interactionism respectively, ignores significant emotional concerns leaving the need for a holistic perspective of human experience unsatisfied.

While Symbolic Interactionists recognize interpretation of symbol as being an important construct, their consideration of meaning is primarily cognitive (LaRossa & Reitzes, 1993). However, as my research about family ritual suggests, in the context of the loss of a child, meaning adopts a strong emotional connotation. Our understanding of symbol may also exist on a more emotional than cognitive level. The symbolic, sacred, creative, and healing elements of ritual together contribute to the enhancement of meaning in profoundly emotional and spiritual ways. The understanding of meaning in this sense complements cognitive meaning and could, potentially, fill in the existing gap, making the achievement of a holistic theoretical approach possible.

The Family Stress perspective emphasizes adaptive and maladaptive behaviour resulting from cognitive definitions and meanings of stressful or crisis events. Some Family Stress theorists in their examination of the significance of resources have identified financial, material, and educational resources for their impact upon how families perceive situations and manage stress and crisis (Boss, 1987). However, others in the area have realized the value of

families accessing such resources as self-esteem, family cohesiveness and adaptability, communication and various forms of support in troubled times (Hobfoll & Spielberger, 1992). Again, using my own study as a frame of reference, I would suggest that while external resources such as family income can make a substantial contribution to how families manage stress and crisis, acknowledging the importance of internal resources and strengths such as family unity is equally necessary, particularly as these can be used to further our understanding of emotional motivators of behaviour. Where research explores the depths of human experience, the blending of emotional, cognitive, and behavioral elements is necessary.

Contrary to claims of some Family Stress theorists, cognitive appraisal does not appear to be a necessary condition in order for families to manage stress or crisis situations (Boss, 1984; Hill, 1958; Koop & Keating, 1990). Dollahite (1991) also notes the value of definition, but qualifies his appreciation by adding that a distinction should be made between actual and perceived resources, and with this latter point, I agree. I found that the powers of healing may exist without a family's identification of them per se. It seemed that some family and individual strengths develop so gradually, inconspicuously, or unconsciously that family members only recognize their value in hindsight or possibly not at all.

Cognitive definition perhaps adopts greater significance in the search for personal meaning, as Symbolic Interactionsists have already established (LaRossa & Reitzes, 1993). When families are deliberately seeking to attach meaning to their experience of loss, their subjective interpretations increase in significance.

From the interpretation of the data, I observed that the constructs of coping from Family Stress, and of meaning from Symbolic Interactionism, evolve in relation to one another. Among families who experience the terminal illness and death of a child, it seemed that meaning develops as coping progresses, and as coping further progresses, deeper meaning develops. The stories of tributes made to their lost child demonstrate that the families' search for meaning in this loss was in itself healing. And as they healed, the families found themselves more appreciative of the meaningfulness of their lives, and grew as a result.

However, family members who initially were denied or, for whatever reason, avoided the use of ritual, found performance of certain structured and unstructured rituals remarkably healing and meaningful even years after the loss of a child. It was not that long ago that families who experienced late miscarriage, stillbirth, or neonatal death missed the opportunity to name their child, to hold her, to take her picture, or to bury her (Kohner & Henley, 1995). Families like the Roaches may find that because there was no chance to observe ritual before their infant died, its observation becomes more meaningful and more necessary afterwards for the purpose of enhancing coping and meaning, and for the sake of effective closure.

Mourning uncelebrated rituals

The importance of uncelebrated rituals also emerged as a critical theme in the findings. The anticipated rituals that go unobserved after a child dies can instigate chronic sorrow and create a temporary obstacle to the development of meaning and coping. For

those who are in a position to offer their support to bereaved families, understanding the relationship that exists between chronic sorrow and ritual will influence the kind of support they can offer.

For example, as the holiday season approaches, a family might be grateful for friends' expressed recognition that they must be thinking of the child who has died. Close family and friends may provide comfort by being aware that a certain level of chronic sorrow is normal and by being sensitive to the fact that certain holidays, anniversaries and celebrations can reopen the wounds of grief. This awareness might inspire support in other meaningful ways. Continuing to acknowledge the family's loss, mentioning the deceased child in conversation, or sending a simple note of remembrance at the anniversary of the child's death may also be appreciated as continued acknowledgement that the child was special and that he is missed. These are rituals of recognition practiced by others that bereaved families may greatly appreciate. The family are acutely aware that the child is absent during these times. For friends and extended family not to acknowledge the child's absence undermines the grief and loss suffered by the family. Yet the simple acts outlined above have the power to remove much of the isolation associated with grief and can help re-introduce the family into the living community.

For their own part, bereaved families may find that displaying a picture of the child or making some mention of him at a celebration such as the wedding of a surviving brother or sister helps maintain feelings of connection. Furthermore, this act may touch observers,

wordlessly informing them that mentioning the child in the presence of his family is not taboo but is, in fact, precisely what they want.

The offence and hurt expressed by both participating families in response to people's insensitive remarks about the loss of their child revealed some significant problems with how we as a society deal with the subject of grief. Despite the fact that death sooner or later touches us all, most of us are ill prepared to face our own mortality or to comfort those who are mourning someone they deeply loved. When faced with the latter situation, our awkwardness can hold us back from saying anything at all, or our lack of knowledge about what to say prompts us to echo some trite phrase that is empty at best, and insulting at worst.

## Implications for Family Life Education Practice

Family Life Education assumes a proactive stance in the management of crises and problems which I consider relevant to the context of childhood terminal illness and death. Because ritual possesses many strengthening and unifying qualities (McCubbin, et al., 1986), it can be convincingly argued that understanding the benefits of ritual and learning how to adapt ritual according to need is important for all families. By creating and refining meaningful ritual techniques before a crisis such as the loss of a child develops, families may have an advantage in coping, particularly in earlier stages of grief. When the devastation of loss is new, focusing the energy required to adopting new coping methods will present a challenge too great for most families who may then face a prolonged wait to benefit fully from ritual. This perspective is concurrent with

that of Hill (1958), Koop & Keating (1990), and McCubbin (1993), who claim that the accumulation of resources before a crisis is reached strengthens families and better prepares them for managing resulting stressors.

The findings of this study strongly suggested that families grieving the loss of a child need the support that education, understanding, and compassion can establish. As I reflected upon the interviews, I found myself returning to this issue. I have come to see the lack of education about death and dying as a fundamental problem, one that is closely linked to how grieving families are supported or not supported. Death and Dying courses are generally available only to those in the helping professions or to interested university students. It appears, instead, that most everyone might benefit from the kind of information presented in these courses, but at a much earlier stage in their education.

Family Life Educators have the ability to develop programs that could address these needs. Currently senior high schools in Alberta offer "CALM" or Career and Life Management courses which take only a summary glance at the topic of loss. In addition, individual counselling is available as required to children at any school level within the province of Alberta. Should a comprehensive Death and Dying component be incorporated into the junior and senior high school curriculum, the fear and discomfort that children often associate with death could be dramatically reduced. When dying is seen as a natural process, the taboo we have imposed upon death will begin to erode.

Most people suffer a significant loss in life of some kind, yet most lack the information and tools necessary for addressing their needs to cope with and find meaning in their situation. In addition to supplying students with information pertinent to the subject of death and dying, Family Life Educators could help students explore a variety of meaningful and healing rituals. Wolfelt (1993), describes wonderful rituals designed for children and their families grieving the loss of a parent that could be easily adapted and taught in a variety of circumstances (Appendix F). As well, Family Life Educators could facilitate relevant class discussion which would lend itself to more open communication at home, and allow children and parents to explore their ideas and beliefs as a family. An interdisciplinary project involving the benefits of ritual when loss is experienced could also be assigned. In particular, the celebratory and creative elements of ritual might hold tremendous appeal to children. This approach might inspire students' imaginations and would have the added advantage of actively involving the children's parents in what their children are learning. Not only would parents have the opportunity to learn something valuable from their children, but more people would be reached this way.

Family Life Educators could also help parents understand how the benefits of ritual can facilitate coping and contribute to family strength and closeness. The application of family ritual in preserving special memories and inspiring meaning could be emphasized and encouraged in a variety of loss situations. This information could be presented in newly created programs exploring

a variety of coping techniques and resources, or in modified parenting programs that are already established.

Family Life Educators are experienced in program delivery and would thus be able to develop programs of this kind that could either stand alone or be taught in conjunction with other essential topics. Were the topic better understood and more openly discussed, bereaved families might find friends and extended family members able to give them the kind of support they need.

## Indications for Future Research

I chose to explore how families cope and find meaning in their loss of a terminally ill child because I originally hoped to compare how families find the purpose and meaning of ritual changes when a child is dying and has died. As it turned out, an adequate comparison could not be made in the Roaches case because Lindsay died so early in life. This comparison would also have been impossible had I studied families whose experience had been the unexpected loss of a child, and yet in many ways the findings of this study can be extended to families who have lost a child to sudden illness, accident, suicide, or murder. Ritual can enhance coping and meaning in all forms of significant loss. A study that eliminates my objective could include families who have coped with these various kinds of loss and would likely result in a significantly larger sample.

Rituals are often considered within a cultural context, and it is also recognized that grieving varies according to cultural influences. For this reason, conducting a cross-cultural study of the role of ritual

in families' efforts to cope with, and find meaning in, the terminal illness and death of a child might yield interesting results.

Additionally, a larger, more varied sample might incorporate families who are at different life cycle stages to further the understanding of how meaning and coping evolve over time. This kind of study would also permit closer examination of the occurrence of chronic sorrow relative to each life cycle stage. A longitudinal study might afford the same kind of information, yet complexities inherent in the method may make this a less desirable choice.

Including negative cases might also be an instructive means of establishing support for the findings of this research or to achieve a more holistic understanding.

In following any of the above suggestions, the difficulties encountered in obtaining a representative sample should be realized before these kinds of investigations are undertaken.

The findings of this study support previous claims that there are differences in how males and females cope with loss (Klass, 1986). Variations in individual family members' coping repertoires included the use of ritual. Whether perceived gender differences in the practice of ritual are related to difficulties in the progression of grieving may also merit consideration in future investigations.

Although parents are most often chosen as subjects for bereavement studies, this research acknowledged grieving as a family experience. Future work done in this area should recognize the incredible value of including children as participants. Their loss is profound, and their voices deserve to be heard.

Unfortunately, the overwhelming tone of existing research of childhood terminal illness is negative. Contrary to previous studies, this topic was broached with a more positive framework in mind. It has been my objective to see if families can find healing and meaning through their use of ritual largely because I believed it was essential to provide families with an opportunity to understand that despite tragedy and loss, hope can be found. If anything, my work with the Michauds and Roaches confirmed this belief. And, I feel, there is a need for further research in this vein.

## Limitations

A rich case study approach involving two families was selected for this study. Although this choice may be subject to criticism on the basis of generalizability, it is widely recognized that bereavement is uniquely experienced by those who undergo significant loss. Furthermore, this method afforded tremendous depth of detail which seemed most befitting to achieving an understanding of this complex topic.

A larger sample would also be likely to include a fuller range of family structures, resources, and strengths. Additional comparisons of ritual's enhancement of meaning and coping would not necessarily be more vivid, but the spectrum of experiences might be greater.

Because my sample was small and the experience of loss is unique for every individual and family, forming generalizations based on the findings was a task that had to approached cautiously. From the start I recognized that what works well for one family or family member may not do so for another. And yet I feel that I can

confidently maintain that rituals can play a significant role in families who are coping with the loss of a child. What I would not try to argue is that any form of ritual should be imposed upon a family or any of its members. A family's personal adaptation of ritual over time and circumstance imbues the act with meaning and it is only when family ritual is meaningful that it possesses the power to heal.

## Concluding Thoughts

Adrien's and Lindsay's families' stories are now known. Yet black print on white paper reveals only so much. The reader did not hear a father's voice falter; or see a mother's eyes red with tears. I am honoured that the Michauds and Roaches chose to share their stories with me. They and other families who have had to travel alone on the same paths of hurt and healing have my deepest respect.

My research has led me to believe that participating in ritual nurtures the spirit. With this recognition, I sincerely hope that my investigation has meaningful application for those grieving the hopes, dreams, and expectations that die with a child. I wish the same for those who are in a position to offer bereaved families both support and comfort, whether in a personal or professional capacity.

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APPENDIX A

Poster for the Notification of Participants

# VOLUNTEERS WANTED

## How have families found meaning and coped with the terminal illness and death of a child?

**If your family has experienced the death of a child (under the age of thirteen) due to terminal illness more than a year ago, you are invited to share your story.**

**Research about special times families have shared when a child has been terminally ill and has died is being conducted by a graduate student at the University of Alberta.**

**If you and your family are interested in volunteering for this study, or if you wish to have more information, please contact the department of Human Ecology at 492-5385 and ask for Carolyn.**

# APPENDIX B

## Participant Information

To be confirmed by telephone.

Study of how families find meaning and cope with the terminal illness and death of a child


Researcher: Carolyn Pounder
Graduate Student
Department of Human Ecology
University of Alberta
492-5385

Adviser: Dr. Dianne Kieren
Professor
Department of Human Ecology
University of Alberta
492-5770


Participant requirements:

1) The family has experienced the death of a terminally ill child who was under the age of thirteen.

2) The death of the child occurred at least one year before the interview.

3) At least one adult and one child (over the age of seven) are willing to be interviewed.

4) Participating family members are able to understand and speak English.

5) Families are able to be interviewed twice for up to 2 hours a session.

6) Participating family members may be contacted by the researcher to discuss the results of the study. This may be done in person or over the phone.

7) Participating family members must sign a written consent form. For children under the age of 18 both parental and child consent is needed.

Families who meet the above requirements and are interested in volunteering for this study will be contacted to arrange interview times. Interviews may be held in your home or at another location to be agreed upon by the participants and the researcher.

During the interviews you will be asked questions about your experiences with the illness and loss of the child in your family. You may refuse to answer any questions which you are not comfortable answering. All interviews will be tape-recorded. The tapes will be destroyed following transcription. Neither the first or last name of anyone in your family will be attached to the transcribed stories you tell. All of your responses will be identified by a number or by a name other than your own.

The Participant's Rights:

You do not have to offer information you are uncomfortable in giving. You may refuse to answer any question during the study. It is your family's choice to participate in this research project. If for any reason a participant decides to withdraw from the study, he or she may do so.

Should you have any questions, or concerns about this study please call Carolyn at 492-5385 or Dr. Dianne Kieren at 492-5770.

Thank you for your time and consideration.

# APPENDIX C

## Participant Consent Form*

* All participating family members who are over the age 18 must sign this form of consent. All participating families with children under the age of 18 must indicate consent of the parents to allow their children's involvement. A parental signature is required to show consent. In two parent families the signature of both parents is needed.

### Study of how families find meaning and cope with the terminal illness and death of a child


Researcher: Carolyn Pounder, Graduate Student, Department of Human Ecology, University of Alberta, 492-5385

Adviser: Dr. Dianne Kieren, Professor, Department of Human Ecology, University of Alberta, 492-5770


The purpose of my research study is to understand how families find meaning and cope when faced with the terminal illness and death of a child in their family. Special emphasis is placed on activities or events that your family shared that made your experience a little easier, more memorable, or that brought you closer together as a family during this difficult time.

As participants your family has the following rights:

1) All family members have the right to refuse to answer any question at any point of the interview.

2) You may stop the interview at any time.

3) You may withdraw from the study at any time.

4) You may call the researcher with any questions or concerns you might have about the study.

As participants your family will be involved in the following ways:

1) You will be interviewed together twice for up to 2 hours each time.

2) You may be contacted to discuss the results of the research study. This interview will be up to half 1/2 hour in length and may be held in person or over the phone. If you wish to have a report of the results, a copy will be given to you.

3) The interviews will be held in your home or at another location to be agreed upon by your family and the researcher.

4) All interviews will be tape-recorded and later transcribed to written form.

5) Codes or names other than your own will be used in place of your first and last names so that your identities are protected.

The researcher and the research supervisor will have access to all information in the interviews, but your names will not be attached to the recorded or written material. The information that you and your family give during the interviews may be used in future publications, reports, or presentations. Again in each of these cases your real names and other identifying information will not be used.

Risks and Benefits to the Participants:

There are no known risks to the families participating in this study. But some painful memories may resurface either during or some time shortly after the interviews are held. There are no direct benefits to participating in this study, yet many people who have participated in research of this kind have found the chance to tell their story personally helpful, and the chance to help others who face similar situations rewarding. Your family's involvement is important to the understanding of how families can cope and find meaning when faced with the death of a child.

Please read the following and sign in front of the researcher:

I _____(please print your name) agree to be a volunteer in this study. I understand the purpose of this study and am aware that all my interviews will be tape-recorded and later transcribed. I understand my rights including that I may withdraw from this study at any time. I have read the above form and I have been given my own copy.

If children who are under the age of 18 wish to participate, parents please read the following and sign in front of the researcher. If yours is a two-parent family, both parents' signatures are needed.

This is to certify that I _____(please print your name) agree to the participation of my child(ren)

This is to certify that I _____(please print your name) agree to the participation of my child(ren)

_____(parent please print child's name)

_____(parent please print child's name)

_____(parent please print child's name)

Date_____Participant's signature_____

Researcher's signature_____

Witness's signature_____

## Participant Consent Form For High School Age Children

### Study of how families find meaning and cope with the terminal illness and death of a child


Researcher: Carolyn Pounder
Graduate Student
Department of Human Ecology
University of Alberta
492-5385

Adviser: Dr. Dianne Kieren
Professor
Department of Human Ecology
University of Alberta
492-5770


The purpose of this research study is to understand how families find ways to cope and find meaning when faced with the terminal illness and death of a child in their family. Special emphasis is placed on activities or events that your family shared that made your experience a little easier, more memorable, or that brought you closer together as a family during this difficult time.

As participants your family has the following rights:

1) All family members have the right to refuse to answer any question at any point of the interview.

2) You may stop the interview at any time.

3) You may withdraw from the study at any time.

4) You may call the researcher with any questions or concerns you might have about the study.

As participants your family will be involved in the following ways:

1) You will be interviewed together twice for up to 2 hours each time.

2) You may be contacted to discuss the results of the research study. This interview will be up to half 1/2 hour in length and may be held in person or over the phone. If you wish to have a report of the results, a copy will be given to you.

3) The interviews will be held in your home or at another location to be agreed upon by your family and the researcher.

4) All interviews will be tape-recorded and later transcribed to written form.

5) Codes or names other than your own will be used in place of your first and last names so that your identities are protected.

The researcher and the research supervisor will have access to all information in the interviews, but your names will not be attached to the recorded or written material. The information that you and your family give during the interviews may be used in future publications, reports, or presentations. Again in each of these cases your real names and other identifying information will not be used.

Risks and Benefits to the Participants:

There are no known risks to the families participating in this study. But some painful memories may resurface either during or some time shortly after the interviews are held. There are no direct benefits to participating in this study, yet many people who have participated in research of this kind have found the chance to tell their story personally helpful, and the chance to help others who face similar situations rewarding. Your family's involvement is important to the understanding of how families can cope and find meaning when faced with the death of a child.

Please read the following and sign in front of the researcher:

I _____(please print your name) agree to be a volunteer in this study. I understand the purpose of this study and am aware that all my interviews will be tape-recorded and later transcribed. I understand my rights including that I may withdraw from this study at any time. I have read the above form and I have been given my own copy.

Date _____Participant's signature_____

Researcher's signature_____

Witness's signature_____

## Consent Form For Junior High School Age Children

I am a University student studying families in which a child is very sick and dies. I understand this happened in your family. I want to hear about what special things your family did together. Your ideas are important to me.

If you decide to be part of the study, we will all meet together.

I will have some questions for your family. You can answer any questions you want. You do not have to answer if you do not wish to.

You can also ask me any questions.

You may stop the discussion at any time.

I don't have to use your real name, so you can choose a name that you like.

The things you and your family tell me about could bring up some sad memories. Please tell me if you are sad. You can decide at any time that you do not want to part of the study. Not everyone in your family may want to take part. It is your choice to be a part of this study.

Please read the following and sign in front of the researcher:

I _____(please print your name) agree to be a part of this study. I understand what the study is about. I understand that I may stop being part of this study at any time. I can stop even if I sign here. I have read this form and I have been given my own copy.

_____(please print your name)

Date_____(please sign your name)_____

Researcher's signature_____

Witness's signature_____

Consent Form For Elementary School Age Children

To be read along with and explained to elementary school age children.

**I am a University student studying families in which a child is very sick and dies. I understand this happened in your family. I want to hear about what special things your family did together. Your ideas are important to me.**

**If you decide to be part of the study, we will all meet together.**

**I will have some questions for your family. You can answer any questions you want. You do not have to answer if you do not wish to.**

**You can also ask me any questions.**

**You may stop the discussion at any time.**

**Since I won't be using your real name, you can choose a name that you like.**

**The things you and your family tell me about could bring up some sad memories. Please tell me if you are sad.**

**You can decide at any time that you do not want to part of the study.**

**Not everyone in your family may want to take part. It is <u>your</u> choice to be a part of this study.**

**<u>Please read the following and sign in front of the researcher</u>:**

**I _____(please print your name) agree to be a part of this study. I understand what the study is about. I understand that I may stop being part of this study at any time. I can stop even if I sign here. I have read this form and I have been given my own copy.**

**_____(please print your name)**

Date_____

Researcher's signature_____

Witness's signature_____

# APPENDIX D

## Sample Questions*

* Please note this is only a sample interview guide. During the actual interviews, some of the above questions were omitted, asked in a different order, or different questions arose.

Families do many things together. They celebrate holidays and birthdays. They spend time together at mealtime or bedtime. They may have some belongings, stories, or poems that are important to them and that they like to share from time to time. There may be something special that they only do as a family. These events and activities are called family rituals. Some of the things you do as a family may have become more important to you during (deceased child's name) illness or after his/her death. I am trying to understand how these kinds of events or activities have been important to families during a child's terminal illness and after his/her death.

1) Can you tell me a little about your family?

2) What was (deceased child's name) like?

3) What were your dreams for your child?

4) Can you describe some of the challenges you faced during his/her illness?

5) What can you tell me about what some of the things you have done or made to help you remember and honour the child? How is it connected to your memories of him or her?

6) Was there anything that your family did together to help you cope with the child's illness - something that made things a little easier or made your time together more special?

7) Was there anything that your family did together to help you cope with your loss - something that made things a little easier or made your time together more special?

8) Did all of you take part? What did being a part of it mean to you?

9) What meaning did (the ritual the family has described) have for you? Did it have the same meaning for all of you?

10) Can you describe some of the challenges you faced after his/her death?

11) What has going back to the cemetery meant to each of you?

12) Did you continue doing (the ritual the family has described) after he/she died? What were your reasons for doing so?

13) Did (the activity the family has described) change at some point? Why?/Why not?

14) Did each of you continue to take part? Did each of you continue to like being a part of it?

15) Did the meaning change for any of you over time?

16) Have family traditions become more important to you since this experience? If so in what ways?

17) Has your experience changed you personally? as partners? as parents? as a family? In what ways?

18) Do you feel that you have found meaning in your experience of loss? In what ways?

# APPENDIX E

## Resource Sheet for Participants

Alberta Mental Health Services
427-4444

Bereavement Services
Services
group & private counselling
(contact Susan Logan of Y.W.C.A.)
423-9922

Bereavement Society of Alberta
482-5677

Bereavement Support
(contact Paula Brindley at
Grey Nuns Hospital)
450-7000

Catholic Social Services
432-1137
424-3545
454-8515
471-1122
439-4673

Community and Social Services Information
424-3242

Compassionate Friends
986-3582

Distress Line (Bereavement)
482-4357

The Family Centre
423-2831

Emergency Social
427-3390

Edmonton Social
Services
428-5890

# APPENDIX F

The following two rituals were written for children and their families who are grieving the loss of a parent, however, both can be adapted to a variety of circumstances, including grieving the loss of a child (Wolfelt, 1993).

## Candle ritual

This technique can be used to help children see and understand that their love for someone goes on even after a death. In fact, many kids, directly of indirectly, will teach you that this is often a question they have within.

To enact the candle ritual, you hold one candle and say, "When you were born you had a gift to give love and receive love. This gift is like a light; it makes you feel warm and happy."

Then you light the candle that represents the child and say, "At first you got close to your mom. She probably held you and fed you. You felt very close to her."

"Your dad also loved you very much. He played with you, he held you, he smiled at you, he played games with you. You felt close to him (put the child's candle representing the father until it lights) and you lit a love light with him too."

"Last year your dad had a heart attack and he died. The warm, loving part of him was gone (explain that you will now put out the light representing the dad). But you have kept on loving him even though he is dead, and your light has stayed burning."

"You have helped me understand that you miss your dad and sometimes you feel very sad that he can't be here with you. But the nice thing is you don't have to blow out your love light that is lit for him. You will always have memories of your dad and be able to remember the love he had for you."

"Your candle of love for your dad will even stay lit as you love other people in your life. You won't want to let anyone try to take this love you have for your dad away from you."

As you enact this ritual, you want to pause from time to time and be certain the child is following you through the story. Children sometimes have questions or want to add to the story. Watch for non-verbal indications about anxiety or questions they might have. Your natural pauses will invite the child to teach you.

Appropriate closure when using this tool is very important. You don't just quickly end it and blow out the candles. You explain that even though we will now blow out the candles (invite the child to blow out the candles when she is ready), the love the child has for her dad will go on and on. The beauty of this tool is that it can be adapted to a variety of situations. I have also used this ritual with adults and found it to be very healing.

## Memory ritual

I often use this technique with the child's entire family or significant others. This is where you place two or three large candles in the middle of a table. Around the outside of the table are small candles (one in front of each person who will participate in the ritual). The purpose of this ritual is to assist in memory work. There is a natural bonding that takes place among the participants as they share memories of the person who died.

"We come together tonight to remember someone you all loved. Let's start by listening to a piece of music that you mom like very much." At this point everyone is circled around the table with a small candle in front of them. Upon completion of the music, I (or whomever) often read something related to memories. One of my favourites is "We Remember Them."

We Remember Them

In the rising of the sun and in its going down,
we remember them;

In the blowing of the wind and in the chill of winter,
we remember them;

In the warmth of the sun and the peace of summer,
we remember them;

In the rustling of the leaves and the beauty of autumn,
we remember them;

When we are weary and in need of strength,
we remember them;

When we are lost and sick at heart,
we remember them;

When we have joys we yearn to share,
we remember them;

So long as we live, they too shall live,
for they are now a part of us,
as we remember them.

You now invite the person to your left to simply share a memory of the person you are there to honour. There is often silence, tears, and laughter as you progress around the circle. After everyone has shared a memory you can close with an additional piece of music. Or, someone may have a reading or poem that is appropriate for closure. What an excellent way to include everyone in remembering the person who died! Children and adults often find this to be a powerfully healing ritual.

A special note: Some people think you should always debrief participants after this ritual. I disagree. I wouldn't have used it in the first place if I didn't trust that people could not only survive it but find it healing. Yes, it often creates a safe place to embrace sadness, but that's O.K. With rare exception, I explain that afterwards it's often nice to just have some quiet alone time to be with your memories. You maintain a supportive non-verbal presence, but don't get in the way of healing by [over-processing] the experience.

Reproduced with the permission of, and written by Dr. Alan Wolfelt, Director for Loss and Life Transition, 3735 Broken Bow Rd., Fort Collins, CO 80526 Healing the Bereaved Child: Grief Gardening, Growth through Grief and Other Touchstones for Caregivers 1996, Companion Press, Fort Collins, CO (970) 226-6050.